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A narrative study of the illness experience of fibromyalgia in South Africa

A dissertation presented to

The Discipline of Sociology

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ABSTRACT

This thesis presents the findings of an exploratory study undertaken to investigate the illness experience of fibromyalgia in the context of South Africa. It contains the literature review and conceptual framework that guided the study. The theoretical discussions reflect the approaches to health and illness, illness experience and narrative study, context, diagnosis, prognosis, sickness, illness career, treatment, institutional interactions and social support. Following this, the methodological approaches and tools used in conducting this study are explained. In-depth interviews and diaries were used to collect narratives from 15 participants and one practitioner. Additionally, a brief media content analysis was included in order to assess the public perceptions of fibromyalgia in South African news articles. The themes of legitimacy, credibility, flexibility, and accommodation are continually developed throughout the thesis. The Analysis of Findings chapter presents and discusses the evidence gathered from the investigations undertaken in this study. This chapter shows how the contested and confusing illness experience of fibromyalgia can be understood, by viewing the interactions that patients have with their practitioners, families, peers and colleagues. The meanings ascribed to fibromyalgia as a label, and the uncertain prognosis attached to the diagnosis, as well as infrequently effective treatment options are explored here. The gains found in successful practitioner-patient interactions, and the limitations of medical aid coverage for chronic conditions like fibromyalgia in South Africa are discussed in this chapter. The role of family and peers, as well as workplaces and colleagues in offering support to those living with fibromyalgia is analysed. Finally, the conclusions arising from this study are presented, and recommendations for areas of future engagement and research are offered in order to attain a better understanding of the experience and impact of fibromyalgia in the South African context.

DECLARATION

I declare that this dissertation is my own unaided work. It is submitted for the degree of Doctor of Philosophy in the University of the Witwatersrand, Johannesburg.

It has not been submitted before for any other degree or examination in any other university.

_____

Silvie Cooper

_____ day of _____, 2014

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INTRODUCTION

This thesis focuses on the experiences of people who live with medically ill-defined conditions. The topic is explored through a narrative analysis of fibromyalgia (a musculo-skeletal pain disorder) in South Africa (SA). The research undertaken herein relates to the broad topic of contested and chronic illnesses. These kinds of conditions traditionally fall under the scope of Medically Unexplained Symptoms (MUS) and are characterised as being "incompletely biomedicalized" (Dumit, 2006; Jutel, 2010). This means that while there is the ability to identify and label a condition within the realm of biomedicine, the explanations of causation, prognosis and treatment are less clearly defined. The conditions are 'contested' to the extent that scepticism and uncertainty are abound in the experiences of those with the illness. Patients with these conditions are continually challenged to show, articulate and respond to their symptoms in ways that convince themselves, practitioners, institutions and social networks that their experience is legitimate, and medically and socially real. Studies in this area straddle many disciplines, including the social sciences and various strands of medicine.

Pain (a characteristic symptom of many conditions but particularly as seen in fibromyalgia experience) often confounds patients, practitioners and their social networks alike, as there is multiplicity in the meanings and manifestations, which makes identifying causes and developing effective responses an arduous task. As Raff et al (2014: 79) explain, "chronic pain is common, affecting around one in five patients in primary care. It may occur even more frequently in older individuals, whose presentation is often complicated by age-related physiological changes, comorbidities and multiple medications [...and] chronic pain may have a significant impact on health-related quality of life and may be difficult to manage". Given the prevalence of chronic pain and the complexity of the phenomenon, it is important to understand how people approach and live with pain pervasive conditions.

In speaking about rheumatoid arthritis (RA) and comorbidity of depression, Pillay (2012: 10) notes that SA "presents a unique context in view of its cultural, ethnic and socioeconomic diversity". Pillay (2012) also asserts there is a scarcity of literature that looks at the prevalence of depression and the particular psychosocial factors related to the population of

RA patients. As RA is another form of musculoskeletal pain with an overlapping symptomology to fibromyalgia, it is a relevant example, and a lens through which the broader picture of chronic pain can be viewed in the context of SA. There is limited understanding of how a condition as elusive as fibromyalgia plays out in this context. In particular, there is limited understanding of how the experience is affected by the specific structure of unequal healthcare access and distribution of resources, practitioners and medications in the country. Investigating the multiplicity and complexity involved in the diagnosis, management, treatment and responses to chronic pain through the case study of fibromyalgia offers opportunities to explain and understand these processes more clearly in SA. The research also contributes to the global literature on this topic.

The study detailed in this thesis aimed to further develop the approaches already present in the growing body of research that interrogates illness experience from the perspective of the person living with a specific condition. The significance of this study lies in the fact that very little research has been undertaken that specifically looks at illness experience in African contexts. The dearth is especially evident when it comes to studies that use narrative inquiry as a methodological approach (Keikelame and Swartz, 2013), as is the case with chronic illness studies in SA.

While there is a growing body of literature being produced by South African researchers, most of the studies reported upon are concerned with clinical guidelines for diagnosing, managing and treating fibromyalgia and other conditions that have pain as a core feature of the symptom experience (Raff et al, 2014; Meyer, 2006; Namane, 2013; Aalbers, 2012; Chetty et al, 2012; Derman et al, 2011; Du Plessis et al, 2009; Whitesman, 2008; Baumann, 2003; Van Schoor, 2012; Koch, 2012; Tikly and Makda, 2009; Hoosen et al, 2013; Shiri et al, 2007; Meyer and Kenny, 2010; Maizels and McCarberg, 2006; Kalla, 2011). However, there is no engagement in any of these studies with the actual illness experience as it manifests in a specific social reality, and the perspective of the patient is absent entirely. The SA context is rarely mentioned in these studies, and the opportunities and challenges inherent in the relations between patients and practitioners, and the healthcare systems they operate within, are not accounted for.

There are other studies that briefly mention the term "fibromyalgia" in relation to the overlap between the condition and other symptoms associated with fatigue, IBS, migraines and spectrum central sensitivity syndromes. The inclusion of fibromyalgia in these articles is often incidental rather than being the primary focus of the research. The explanations offered in the articles listed above are not detailed and have other agendas, such as the effects of particular medications on treatment outcomes, improvement of diagnostic procedures and comorbidity of illness conditions. Moreover, in choosing a medical stance on the issue of chronic pain, there is much lost in the form of the voice of the patients these practitioners interact with and draw upon as study participants. Sociological perspectives on chronic pain in SA are scarce and as such, there is a need for knowledge and research into these areas, which is a justification for the study undertaken and described in this thesis.

In giving a unique insight into the experience of a complex condition like fibromyalgia in the specific context of SA, the research explored in this thesis was innovative and offers fresh perspectives on an emerging phenomenon. Furthermore, by utilising the narratives of those living with the condition there is opportunity to understand how people experience diagnosis, prognosis, treatment, management, and interactions that are inherently complicated by the contested and confusing nature of fibromyalgia. The research undertaken was able to explain what knowledge is received and how it is used in the continual process of clarifying the meanings, experiences and outcomes of living with fibromyalgia. The research simultaneously slots into a growing body of knowledge centred on chronic illness experience, and furthers the available explanations of how people enact health behaviours and manage conditions like fibromyalgia in the particular context of SA.

By bridging the fractures between patient experience and medical perspective, the research makes a useful contribution in learning how people with chronic pain conditions like fibromyalgia are able to navigate through an often challenging illness experience. More specifically, the study investigated the ways in which people living with medically ill-defined conditions are able to make sense of their health status and treatment options available in the SA context. The ways in which a patient draws on government, biomedicine, institutions,

family and social networks to navigate their way through this contested and confusing illness experience was explored. The study aimed to explore the processes linked to legitimising fibromyalgia as a disease and the individual as a patient, as well as examining experiences of de-legitimisation that emerge in the face of uncertain prognosis and ineffective treatment options.

The study aimed to explain and understand the experience of fibromyalgia in the SA context. This was achieved by uncovering the dominant views of health and illness that contribute to the social construction of an illness experience. In offering an explanation of the trajectory of fibromyalgia patients' illness experience through interactions with institutions, practitioners and social networks of family and friends, an exploration was undertaken of the ways in which people living with fibromyalgia negotiate through the "chaos and confusion", competing health belief systems, care and treatments options, and draw on institutional and social support in order to make sense of their illness experience (Aggleton, 1990).

The objectives of the study were therefore:

- Understanding the ways in which diagnosis affords the patient entry into a legitimate social 'sick role' through the acquired medical label, and confirms their experience as medically and socially real, but then subsequently rejects their experience when biomedicine cannot adequately account for the causes, effects and treatment of the conditions
- Investigating the role of prognosis as a site of contestation, legitimacy and uncertainty.
- Explain the context in which this study was conducted, specifically highlighting the structural factors that shape healthcare in SA, the gendered dimensions of fibromyalgia and the popular notions of the condition found on the internet and other media sources.
- Unpacking the process of diagnosis by exploring the narratives of people living with fibromyalgia. By showing the particular junctures that are significant in the pursuit and attainment of the label of fibromyalgia, it can also be seen how this label is subsequently used in interactions with practitioners, families, institutions and broader

social networks.

- Understanding the recommendations for flexibility, adaptation, acceptance and reflexivity on the part of patients and those they work with in managing fibromyalgia. Through this, an explanation of why this is process is particularly challenging in the face of immovable social structures and interactions is offered.
- Viewing the range of treatments drawn on by the study participants in the course of their illness career with fibromyalgia and the implications that exist within the experimental approach taken by many.
- Examining the role of social support and its various forms and functions in addressing and responding to a complicated and unpredictable condition like fibromyalgia.

The sociological significance of this study is that investigating these conditions allows for perspectives to emerge around medical knowledge, diagnosis and treatment processes, the 'sick role' and legitimate illnesses/diseases and social life disruption. By exploring "chaos" narratives, a better understanding can be gained of the paths followed by patients who have no clear prognosis for their illness. Furthermore, the impact of institutional interactions and social support on the experience of contested chronic conditions can be viewed through these investigations. An in-depth exploration of these questions, specifically in the SA context proves innovative and meaningful, as currently there is a need to expand research into these areas (Aikins and Marks, 2007). Additionally, in capturing these broader theoretical questions, the study adds to the existing body of knowledge in this field.

It is of particular significance that this study provides insight into the general experience of patients diagnosed with medically ill-defined conditions who operate in a context that is unequal in its wealth and health distributions. Biomedicine, the institutions and economic forces that dominate healthcare in SA, and the social relations that shape an illness experience, are examined by exploring how patients negotiate their condition. Dubin (2010: 186) notes that "sickness and illness cannot be interpreted as the sole products of biological disorder. A critical understanding of the social and cultural components of health and illness is necessary to provide an integrated approach to medical care". The specific lens of fibromyalgia offers a unique opportunity through which the picture of these processes, institutions, actors, roles and contexts can be effectively captured and understood. This thesis

is therefore meant to make a contribution by filling in some of the gaps that currently exist in the broader discourse on this topic.

This qualitative study used interviews and narrative diaries as the main research methods. The study focuses on the manner in which people living with medically ill-defined conditions negotiate their way through the illness experience, and continually face processes of legitimizing and questioning their state of health. The extent to which the personal experience of illness is shaped by broader social, political and economic forces of culture, as well as institutions, biomedical practice and scientific and administrative authority was a key concern of this study. In addressing conditions that are recognised by the biomedical sphere but are also inadequately explained and dealt with, the impact on the individual living with the illness become sociologically interesting and significant. This conversion occurs in the wider context of power, social control and hegemonic discourses around health and illness and qualifying categories for the experiences of both.

This thesis contains the literature review and conceptual framework that guided the study. The theoretical discussions contained in that chapter reflect the approaches to health and illness, illness experience and narrative study, context, diagnosis, prognosis, sickness, illness career, treatment, institutional interactions and social support. Following this, the methodological approaches and tools used in conducting this study are explained. The themes of legitimacy, credibility, flexibility and accommodation are continually developed first in the literature review and later in the Analysis of Findings chapter where the evidence gathered from the investigations undertaken in this study are presented. This chapter shows how the contested and confusing illness experience of fibromyalgia can be understood by viewing the interactions that patients have with their practitioners, families, peers and colleagues.

The meanings ascribed to fibromyalgia as a label and the uncertain prognosis attached to the diagnosis as well as infrequently effective treatment options are all explored in this chapter. The gains found in successful practitioner-patient interactions and the limitations of medical aid coverage for chronic conditions like fibromyalgia in SA are discussed in this chapter. The

role of family and peers as well as workplaces and colleagues in offering support to those living with fibromyalgia is also analysed. Finally, the conclusions arising from this study are presented and recommendations for areas of future engagement and research are offered in order to attain a better understanding of the experience and impact of fibromyalgia in the SA context.

LITERATURE REVIEW

Fibromyalgia is a condition characterised by confusion, contestation and uncertainty. It is defined by multiplicity and the inability to locate it singularly into one disease category. In undertaking a sociological study of the experience of fibromyalgia in the SA context, it was important to gather literature from a range of sources, including studies related to the fields of pain, psychiatry, nursing, rheumatology, clinical practice, patient education and sociology among others. The literature review will first discuss the general context in which this study occurred. This included the characteristic features of SA healthcare, the gendered dimensions of fibromyalgia as well as the perceptions of the condition as they are propagated in the media, particularly on the internet. Following that, an explanation of fibromyalgia as a medical diagnosis will be presented.

Other components of the literature review speak to the processes and mechanisms of diagnosis and the particular function of the label of fibromyalgia for "explaining the inexplicable". This discussion incorporates an understanding of the "recognising attitude" needed by patients and practitioners in order to bring these experiences from the private space of illness into the public space of sickness. Prognosis as a site of contestation and "sickness" as a social construct is also explored through the literature contained in this chapter. Institutional interactions between patients, practitioners, medical aid insurance schemes, workplaces, social support and health knowledge sources, as well as the effects of these processes on the illness experience of fibromyalgia are all discussed in this chapter.

Context

Fibromyalgia

This section offers a working explanation of fibromyalgia (also called FM and FMS in the literature), from medical, sociological, patient narrative and popular media perspectives. These concepts critically informed and explained the research undertaken and the findings that emerged in this process. Thereafter, contextual factors such as the disproportionate way fibromyalgia affects women compared with men, and the stigma that is commonplace in the

experience of the condition are discussed. The particular healthcare structures that shape the ability to attain diagnosis and manage fibromyalgia in SA are explained.

Ablin et al (2012: 585) note that fibromyalgia is "defined as chronic widespread pain (CWP) with allodynia or hyperalgesia to pressure pain, and is classified as one of the largest group of soft tissue pain syndromes". While the aetiology of the condition is not well understood, "it is currently believed to be the result of a central nervous system (CNS) malfunction that increases pain transmission and perception" (Ablin et al, 2012: 585). Fibromyalgia symptoms commonly include "chronic, diffuse, generalized musculoskeletal pain, and aches and stiffness that occur in the absence of joint inflammation or tissue damage" (Cunningham and Jillings, 2006: 258). There is also uncertainty surrounding the prognoses and treatments related to the condition, as well as multiplicity in the manifestation of the symptoms.

Pain and exhaustion are a common part of ordinary human experience, but the critical shift in interpreting these symptoms as abnormal and in need of intervention is what sets fibromyalgia up for both support and derision as a diagnosis. While it is an invisible condition that relies heavily on the patient's telling of symptoms and practitioner's willingness to take seriously the experience as illness, there is sufficient evidence for it to exist as a medical diagnosis (Åsbring and Närvänen, 2004). Participants in this study variously reported sensations of burning, shooting pains, muscular tension and pain, generalised fatigue and sleep disturbance with rest not being restorative. It was possible to describe the manifestations and multiplicity of fibromyalgia as felt by the participants of this study through investigations of their narratives and experiences.

In its position among chronic pain experience, there is credibility gained for the diagnosis of fibromyalgia because it is similar to other, more recognised conditions. Biomedical indicators often fail to capture the experience described by those with fibromyalgia. However, there exists diagnostic criteria for the condition, and as it gains salience in the medical discourse, so too are patients being afforded the diagnosis more readily. Diagnosis relies heavily on the subjective experience of the patient and their ability to communicate it in a manner that can be correctly absorbed by the practitioner during the consultation. This mechanism is not

different from general diagnostic processes (Jutel, 2010). Fibromyalgia pain is distinct from migraine pain for instance; however, one usually experiences both conditions at once.

Therefore, there is much work to be done on the part of the patient and the practitioner in arriving at the conclusion of what is causing which symptom (Werner and Malterud, 2003; Åsbring and Närvänen, 2004). Fibromyalgia pain can be dominant in the schema of the individual's illness, or dormant, underscoring the generalised sense of being unwell. In its dormant form, it is seen to emphasise and worsen other conditions that take precedent and require urgent attention. This means that either the pain is overwhelming and can be pinpointed as a cause of being sick, or it can exaggerate felt symptoms of other conditions, such as bronchitis, migraines and IBS. Understanding how fibromyalgia manifests in these multiple ways and how people with the condition experience this and talk about it was an important component of this study.

Meyer (2006) explained that fibromyalgia can be understood as a spectrum condition, along with other pain disorders and has a genetic basis. Fibromyalgia is "a chronic widespread pain disorder estimated to affect 2% to 5% of the US adult population and 05% to 5% of other Western populations… [and] with growing recognition of fibromyalgia by patients and health care professionals, more people are seeking medical help for chronic pain conditions and making frequent visits to their health care practitioner" (Arnold et al, 2012: 488). The American College of Rheumatology (ACR) developed diagnostic guidelines in the early 1990s, which have been updated as the condition became better understood. Currently, if a patient experiences three or more months of continual, widespread musculo-skeletal pain, and responds to 11 out of 18 "tender points" when pressure is applied, then they meet the diagnostic criteria for fibromyalgia (Meyer, 2006).

Berger et al (2007: 1498) explain the multiplicity of fibromyalgia makes the condition "typically difficult to diagnose. While various tests may be ordered to rule out other possible causes of patients' symptoms, such as rheumatoid arthritis and lupus, none is sufficiently sensitive or specific to establish a diagnosis of FMS". According to Barker (2011), between two and five percent of the U.S population live with fibromyalgia. The ratio of female to

male patients sits between 6:1 and 9:1 (Sim and Madden, 2008; Barker, 2011). It is unclear how many people are affected by fibromyalgia in SA, but Govender (2004: 10) estimates that the prevalence rate of the condition is around three percent in the general population. This lack of statistical evidence is indicative of the status of fibromyalgia in SA, both medically and socially. This also means that when investigating the issues, narratives, actors and relations that surround medically ill-defined conditions such as fibromyalgia, SA becomes an incredibly useful context in which to unpack this story. There is clearly insufficient medical recognition and support for people diagnosed with fibromyalgia. This is due to the contested nature of the diagnosis and ineffectual treatment options, which cause people with the condition to continually be questioned about the legitimacy of their experience.

Staud (2009) explains chronic widespread pain and fibromyalgia in terms overlapping conditions, peripheral and central factors, and pain modulation in the central nervous systems. Staud (2009: 264) states, "there is substantial overlap among many pain conditions, suggesting common pathophysiological mechanisms… [And] many chronic pain syndromes are characterized by hyperalgesia and abnormal endogenous pain inhibition". Arnold (2010: 386) explains that "painful stimuli, such as [the type that occur] after an injury, may initiate the process that leads to central sensitization in susceptible individuals. Indeed, many patients with FM report the onset of symptoms after physical trauma or repetitive injuries".

Staud (2009: 266-267) observed that,

> augmentation and prolonged decay of nociceptive input [is found] in patients who have FM and [this] provide convincing evidence for central sensitization in this syndrome. A couple of points related to central sensitization seem relevant for understanding FM pain. First, when central sensitization has occurred in patients who have chronic pain, including patients who have FM, little additional nociceptive input is required to maintain the sensitized state. Thus, seemingly innocuous daily activities may contribute to the maintenance of the chronic pain state. Second, the decay of painful sensations is prolonged in FM; therefore, patients may not experience robust changes in their pain levels during brief therapeutic interventions.

While this explanation goes a long way to illuminating what is a fairly invisible process, the procedures for discovering these contributing factors have thus far only been applied in a clinical study environment. Therefore, the study undertaken here brings to light an alternative perspective of how these processes play out in the lives of those living with fibromyalgia.

Rosenzweig and Thomas (2009: 227) support this view, stating there is "considerable evidence that fibromyalgia is a disease related to the dysfunction of central pain processing". There is also an important distinction made between peripheral and central sensitisation as the latter "means that central pain processing pathways localised in the spinal cord and the brain are sensitised" (Nijs and Van Houdenhove, 2009: 4). Nijs and Van Houdenhove (2009) explain that central sensitisation occurs when pain-signalling neurons fire in response to low-threshold stimulus, and that the locations and cause of such pain can be difficult to pinpoint. There are also a host of environmental, behavioural and factors that can contribute to the confounded presentation of fibromyalgia. This refers specifically to symptom expressions in people with fibromyalgia and other chronic pain conditions, for instance "maladaptive coping, such as fear avoidance and catastrophising, 'sick role' behaviour, deterioration of social or support network" (Meyer, 2006: 22).

In discussing assessment of patients with chronic pain, Meyer and Kenny (2010: 294) note that the diagnosis "should not be viewed as a single event, but as a continuous process, although initial assessment will be more comprehensive… Chronic pain consists of three dimensions: sensory, affective and cognitive. Assessment and management, therefore, needs to be undertaken according to a biopsychosocial approach". Other conditions should be ruled out before arriving at a diagnosis of fibromyalgia because peripheral sources of pain contribute to fibromyalgia, such as degenerative joint disease, chronic fatigue and headaches. Using the explanation of "central sensitisation" then becomes productive as it highlights the all-encompassing nature of the condition (Ablin et al, 2008; Yunus, 2007; Bellato et al, 2012).

While this is a useful way of understanding of the condition, its limitations bring into focus the *partial* explanation offered in this approach. As with other medically ill-defined conditions, the pain processing and central sensitisation description only explains certain components of a condition characterised by multiplicity, overlap and complexity. Furthermore, the explanation does not extend far enough into the expectation a person can

hold for the experience of fibromyalgia. Additionally, it cannot offer concrete and replicable treatments that work for every patient. The diagnosis of fibromyalgia in this regard does not perform to its full capacity, in terms of providing an attached prognosis and treatment. This in turn undermines the legitimacy of the initial explanation.

Rosenzweig and Thomas (2009) capture the nuances and complexity associated with fibromyalgia as a diagnosis in their discussion of treatment options. They use the label fibromyalgia and fibrositis synonymously while others see fibromyalgia as a clearer and separate clinical diagnosis. They too advocate ruling out other causes of symptoms before attributing the illness to fibromyalgia and characterise the process as a "diagnosis of exclusion". Rosenzweig and Thomas (2009: 228) state that

> Dysfunctions of the pain-processing, neurotransmitter, metabolic, and neurohormonal systems are all implicated in its [fibromyalgia's] pathophysiology. In addition, a history of inadequate sleep, physical or psychological trauma, or certain viruses… has been correlated with a higher incidence of FM symptoms. Stress has also been hypothesized to be a contributing factor for fibromyalgia. Studies have explored psychosocial stresses (high work load and responsibilities, low decision latitude, bullying) and mechanical stressors […] as factors leading to chronic widespread body pain and chronic fatigue.

As Rosenzweig and Thomas (2009) note, the ACR criteria for fibromyalgia have an associated specificity and sensitivity of 85 percent. Despite the explanations available and diagnostic criteria and some useful treatments, "there is still no consensus on the cause(s) of fibromyalgia. [However,] the pathogenesis of fibromyalgia is not completely understood, a number of theories exist" (Rosenzweig and Thomas, 2009: 227). Nijs and Van Houdenhove (2009) show the multitude of causes and situations that bring about the onset of chronic widespread musculo-skeletal pain, and the challenge of viewing and addressing the appropriate aspects in a timely manner. Whether it is an accident or injury, predisposing conditions or illnesses that cause ongoing pain, the result for Nijs and Van Houdenhove (2009: 5) is the continued "activation of local nociceptors that initiate or sustain central sensitisation". Therefore, there are parts of the process of fibromyalgia pain that are well understood. However, there is also often an inability to convert these descriptions into useful, relatable explanations that practitioners, patients, and other social actors can draw upon in developing narratives of fibromyalgia experience.

Lupton (2003) contextualises this process within Frank's (1998) typology of **restitution, chaos and quest narratives** that are used to explain illness experience. Acute illness is described through a 'restitution' narrative, where the individual recognises symptoms, enters medical care, receives treatment, then recovers, and returns to their previous state of wellness. In this view, illness is episodic rather than enduring and repeatedly disruptive, and comes to a resolution with the crucial and successful input of medical practitioners. In cases of illness that convert into chronicity and where recovery may not be an immediate option, delegitimation of the individual and the condition often occurs. This is exacerbated in cases where biomedicine fails to fully account for the causes, prognoses or treatments of a condition. This is due to the hegemony of restitution narratives in lay and medical explanations of illness experience and the rejection felt when these expectations (symptom recognition, straightforward diagnosis and attached treatment, and recovery) cannot be adhered to, as is the case with fibromyalgia. Lupton (2003: 95) explains that those who are 'deeply' or chronically ill and whose "stories of illness cannot include recovery may be marginalized by the cultural dominance of the restitution story".

The uncertainty about the specific reasons for fibromyalgia's existence allows questions to persist and corrodes the clarification process that emerges during diagnosis. This contributes to the scepticism surrounding fibromyalgia as a diagnosis, the credibility of the illness experience for the patient and the capacity of the practitioner to effectively treat the symptoms (Werner and Malterud, 2003). For those utilising the diagnosis of fibromyalgia and asserting the legitimacy of the label, these questions are somewhat irrelevant, as they accept the explanations offered above as sufficient to diagnose and then treat the patient's symptoms. For them, it offers enough clarity to confront the symptoms and afford the patient the care and resources necessary to cope. However, this picture becomes less precise when viewing different levels of acceptance for fibromyalgia as a clinical diagnosis in the medical fraternity, and in patient experience, as well as in the institutions, networks and society all these stakeholders interact within.

According to Van Wijk (1996: 707), "women's health involves their emotional, social and physical well-being and is determined by the social, political and economic context of their lives as well as by biology". This approach to gendered health outcomes and care can usefully be explained through the case of fibromyalgia, as it has patterned, but unpredictable manifestations (Cunningham and Jillings, 2006). The prognosis of the condition is sketchy at

times, and so identifying both what triggers the onset and worsening of symptoms as well as treatments that could offer relief is a process fraught with complications. It is a combination of internal, predisposing vulnerabilities and factors, as well as external, environmental and lifestyle conditions that precipitate, perpetuate and aggravate the experience of the illness. In the research presented herein, it was found that the frequency and severity of the symptoms determined the readiness with which participants consulted with health-care practitioners. The nature of the reception from healthcare practitioners further encouraged or discouraged help-seeking. If the individual perceived the practitioner as being dismissive of the symptoms or attempted to diagnose the experience as somatic and psychological, participants in the study immediately moved on. They either went to other practitioners, or to other health systems (such as CAM[1]), or avoided seeking help altogether.

For this reason, Barker (2011: 833) maintains that part of living with fibromyalgia is managing "a constellation of chronic symptoms while coping with medical and public skepticism". Barker (2011) also discusses the fact that coming to a diagnosis of fibromyalgia requires a great commitment on the part of the patient to pursue a better explanation for their illness experience. Furthermore, she explains the integral role of health care providers and practitioners who "believe" in the existence of fibromyalgia. Barker (2011: 834) terms practitioners who are able and willing to diagnose and offer treatment for fibromyalgia as "fibro-friendly". However, as Barker (2011) argues, receiving a concrete diagnosis of fibromyalgia does not necessarily bring relief from pain and discomfort to the person. This is because while there is a sense of validation and legitimization in getting a diagnosis it often does not end medical denigration (Barker, 2011; Undeland and Malterud, 2007). This is related to the relatively limited amount of biomedical evidence and effective treatments available for fibromyalgia, which pushes the individual back into the milieu of confusion and chaos that surrounds medically ill-defined conditions (Barker, 2011).

Sim and Madden (2008: 62) explain that fibromyalgia, like other forms of chronic pain "impacts upon individuals' being in three main ways: bodily constraint, activity constraint, and identity constraint". This in turn affects the individual's ability to function, which fits

[1] Complementary and Alternative Medicine

into the “typology of ‘patterns of living’ [as] proposed by Mannerkorpi et al (1999)” (Sim and Madden, 2008: 62). This typology includes stages of *struggling, adapting, being in despair and giving up.* In turn, there is correspondence with the spectrum of “resistance, accommodation, and acceptance” which is not necessarily a straightforward or progressive process. It requires of the person attempts to achieve a balance between battling against fibromyalgia and accommodating it in one’s life and social identity (Sim and Madden, 2008: 62).

Beyond this process is the wider medical and social acceptance of the person living with fibromyalgia, their condition and associated symptoms. There are also complications found while attempting to accommodate fibromyalgia in individual experience and societal interaction, as there is often a lack of support offered to those living with the condition. The social capital of the individual, and their ability to effectively access medical and social care, are critical to the successful adaptation to fibromyalgia as a chronic condition in one's life (Åsbring and Närvänen, 2004). Additionally, fibromyalgia is not a uniform or lateral condition in its trajectory; it appears with varying severity and therefore responding to the condition can be complicated. A "recognising attitude" is required in developing effective means of accommodating the condition into an individual's life, as is the case with many chronic conditions (Werner et al, 2003).

Werner et al (2003) noted that in attempting to address chronic musculoskeletal pain through a treatment programme, recognition became critical to effective outcomes. In their study, "women described recognition as forms of awareness expressing an attitude… characterized by listening, understanding, confirmation, and acceptance and tolerance" which were received from group leaders and participants in the programme (Werner et al 2003: 492). In acknowledging and recognising the symptoms being experienced as a chronic state of pain, the programme appeared to "contribute to an increased ability to understand and handle various aspects of [the participants'] lives" (Werner et al, 2003: 492). This emphasises the critical manner in which acceptance and recognition for an illness condition promotes visibility of the symptoms as needing intervention, and legitimises the person and their experience. It is a simultaneous process of internal acknowledgement of being unwell and social acceptance in transforming the experience, in order to bring it to the attention of

medical and social care structures. The study undertaken her was able to show how these processes are enacted, and the effects of stigmatisation, disbelief, legitimation and social support in shaping the experience for those living with fibromyalgia in SA.

Gender

Rosenzweig and Thomas (2009: 226) explain, "epidemiological data link FM with female sex, lower socio-economic status, lack of college education, and a history of divorce". Rosenzweig and Thomas (2009: 226) characterise fibromyalgia as "predominantly a disorder of women, seen mostly between the ages of 20 and 50 years. Because of a tendency to run in families, genetic factors are believed to be involved its pathogenesis". Citing Hawley and Wolfe (2000), Barker (2008: 26) explains that fibromyalgia is "highly feminized - approximately 90 percent of those who meet the diagnostic criteria are women".

Gately et al (2007) explains the accumulated effect of viewing health behaviour through the cultural model of health care systems, rational choice, and economic models of decision-making. They also discuss psychological approaches, and the social behavioural model. Gately et al (2007: 935) state, "these approaches offer an extensive list of contingencies that affect the use of services" such as "patient demographic, health beliefs [and] accessibility of care". This clarifies why there is variance in my study population compared with other research findings, and underscores the complexity of this process in attempting to capture a condition and experience that is known for its heterogeneous manifestation and elusive causes.

In confirming through my study that fibromyalgia disproportionately affects women, it is important to explain why this occurs. Arnold et al (2008: 114) states that prevalence rates are "3.4% in women, compared with 0.5% in men". Barker (2011: 833), citing Hadler (1997) and Showalter (1997), asserts that "the feminization of the disorder intersects with cultural stereotypes about women's emotionality and irrationality leading some critics to claim that fibromyalgia is a form of modern day hysteria". For the people involved in my study this was a common experience, especially in the stage of seeking diagnosis. There is interplay

between being articulate as a patient and challenging medical authority through the confounding symptoms being presented. This exchange leads to a diagnostic process that simultaneously affords the person "some degree of validation [but] it rarely [brings] the experience of medical disparagement to an end" (Barker, 2011: 834). Katz et al (2010) discuss the confusion surrounding the reasons for the disparity in diagnosis of fibromyalgia between men and women.

Katz et al (2010: 25) explains that a "gendered discrepancy such as that identified [in terms of fibromyalgia experience] could represent a true physiological difference (patient specific) or, alternatively, a diagnostic perceptual difference (physician specific)". Paulson et al (2002: 238) describe pain as "a common phenomenon in chronic/long-term illness and a quintessential aspect of the human condition, located at the intersection of bodies, minds, and culture". Paulson et al (2002) suggests that while fibromyalgia does disproportionately affect women, this can be attributed to the fact that men rarely report their musculoskeletal pain and the appearance of symptoms occurs in unexpected locations in men compared with women. What this implies is that both at the stage of speaking about pain and in presenting symptoms in anticipated places, which is needed for accurate diagnosis, men are unable to transform the meanings of their pain from subjective experience into medical recognition to worse extents than women (Paulson et al, 2002).

Key in this perspective is also the distinction between the types of pain experienced by men and women, with men experiencing localised chronic pain while women feel generalised pain. In diagnosing pain and exhaustion as fibromyalgia, this difference is important, as women's pain (due to the widespread nature of it) would be more readily characterised under that label than men's pain (Paulson et al, 2002). It is unclear what particular differences there are in the symptoms experienced by men and women in relation to fibromyalgia. However, the reluctance to seek help, variations in manifestations of the condition, practitioner attitudes and relationships, as well as myriad socio-cultural factors associated with pain expression, all contribute to the gendered patterning of fibromyalgia. According to Barker (2011: 835), citing Bird & Rieker (2008),

> Fibromyalgia is a diagnostic label given to medically unexplained symptoms that are widespread in the general public and particularly common among women. Compared to men, women report more chronic ailments, pain and dysfunction; they experience more physical discomfort and corresponding limitations; they have higher rates of depression; they use more prescription and over-the-counter medications; and they have higher rates of healthcare utilization.

All these factors contribute to the gendered nature of fibromyalgia in its epidemiology, and according to Barker (2011), the complex interactions between biophysical, societal and political realities are displayed through these patterns. Åsbring and Närvänen (2002:149) discuss the effect of conditions that are difficult to diagnose and the consequences for "women who are affected by these illnesses [which] can also be considered to raise their stigmatizing potential". Werner et al (2004: 1037), citing Haug (1992), discuss the differences found in relation to morality and women, and explain that "in men the central element is property; in women it is her relation to her body". In the attempt to offer correct care to patients, the right diagnosis must be made and "a clinician's diagnostic skill is strongly determined by professional training, augmented by observations made during the accumulated experience of practice" (Carlson, 2000: 220). This understanding links individual experiences and stories, locating them in the broader structures and workings of society, as well as the organisation that exists around gender and disease within the medical discourses (Werner et al, 2004).

Fibromyalgia presents as a spectrum condition, with multiple symptoms belonging to many diseases. It is sometimes difficult to coherently distinguish which conditions are creating specific symptoms. What is characteristic with fibromyalgia is the pain that is strongly felt by those living with the condition, but is hard to medically see. As found in my study, receiving a diagnosis is considered an achievement, and across the group that participated, the diagnosis was considered a launch pad from which they could come to terms with the condition. This condition, as discussed earlier, is not well understood, has low social and medical credibility, and is frequently inexplicable when interrogated beyond face value. Speaking from a gendered perspective, Werner et al (2003) elaborate that fibromyalgia is often used to label women's "unexplained" pain.

Fibromyalgia is interesting as a condition, because the diagnosis has been incorporated into various levels of medical and social discourse, which suggests it has sufficient credibility to be utilised by practitioners and patients. However, as the diagnosis often cannot go beyond labelling the illness and symptoms being experienced, the legitimacy of fibromyalgia, the associated pain and exhaustion, as well as the patients and their stories are eroded (Barker, 2005). This is not an uncommon phenomenon in the broader schema of medically unexplained conditions; as Werner et al (2003: 502) explain, "women with medically unexplained disorders report several negative experiences in their encounters with health care personnel when telling their story and describing their symptoms". This could be due to the threat and confrontation contained in the experience of fibromyalgia, in that there are elements of the condition that medicine struggles to grasp and explain.

Many authors, in exploring patient-practitioner relations, note the difficulty of gaining credibility faced by women with inexplicable pain to gain credibility, not merely because their symptoms are medically invisible but also because of the discrimination that manifests against their gender in broader society (Werner and Malterud, 2003; Werner et al, 2004; Barker, 2011; van Wijk et al, 1996; Johansson et al, 1999). Carlson (2000: 220) asserts that presently, "the ability of clinicians to accurately diagnose many conditions in women is compromised by large gaps in the biomedical knowledge base, owing to a longstanding, cultural focus on a male norm for health and disease". The importance of this relationship was vividly displayed in Johansson et al's (1999: 1793) study on women's experience of making meaning with pain symptoms where they found that, "physicians were perceived as masterful, and the women patients coped by using strategies such as somatizing, pleading, martyrizing, mystifying and condemning".

This description of patient-practitioner interactions around pain experience showed some of the challenges faced in addressing conditions that are poorly understood and managed within biomedical frameworks and practices, such as fibromyalgia. In seeing the deficiency being due to a historical neglect of conditions that affect women particularly, it is possible to understand how seeking diagnosis and finding effective treatments is so challenging in this context. The study undertaken herein aimed to illuminate some of these issues by specifically

drawing on the narratives of women living with fibromyalgia in SA. This perspective could be assistive to clinicians and patients alike who require different, innovative perspectives in order to completely and accurately understand these elusive conditions, and to effect care appropriately (Carlson, 2000).

The healthcare context of SA

Fibromyalgia as it plays out in SA, with the inequities found in healthcare provision and availability of practitioners, means that the pursuit of an elusive diagnosis has to be undertaken with a certain level of access to resources. This changes the features by which people looking for the diagnosis of fibromyalgia can be defined, because in the SA context this task is shaped tangibly by the interactions produced specifically by the divisions that characterise this country (McIntyre et al, 2007; Coovadia et al, 2009; Beck, 2000; Stuckler et al, 2011). This characterisation of healthcare availability in terms of practitioners and services - and the economic lines along which these interactions - explains why people with elusive conditions like fibromyalgia will typically be wealthier in the SA context. While these people are in the minority of the population, it is important to understand how they are able to attain diagnosis for their condition and utilise the services that are exclusively accessible to them. Coovadia et al (2009: 10) explain the history and expansion of the private healthcare sector in SA and note that,

> This expansion was fostered by an explicit government policy of privatisation, which was specifically motivated by international trends towards an increasing role for the private sector. By the early 1980s, about 40% of doctors worked in the private sector, but a decade later, 62% of general doctors and 66% of specialists were in private practice. Since private specialists generally locate their consulting rooms within private hospitals and admit their patients to these hospitals, the increase in the number of private hospital beds contributed to an even greater movement of specialist doctors into the private health sector. There is a substantial difference in resource availability between public and private sectors; less than 15% of the population are members of private sector medical schemes, yet 46% of all health-care expenditure is attributable to these schemes

Steyn et al (2008: 380), in their study on hypertension in SA, show that people with medical aid insurance who received treatment in private healthcare settings "were no more aware of their condition than those without medical aid. However, medical aid participants took medication significantly more frequently and had significantly better BP [blood pressure] control".

Steyn et al (2008) attribute these differences to the fact that people with insurance have more ability to cover costs while receiving private healthcare and treatment. Steyn et al (2008: 380) explain that the "failure of service provision rather than non-compliance to treatment" is probably the reason for people having insufficient hypertension care, while receiving treatment in public health settings. These differences in accessibility and quality of care are characteristic of the SA context and the historical and current divisions that shape both opportunities and outcomes of health in the country (McIntyre et al, 2003).

Kahn (2011: S34) describes the shifts in population health over the last two decades in SA and explains that the country has

> experienced a complex health transition, which is in line with the experience of other middle income countries […] Mortality differentials in South Africa illustrate an 'epidemiologic polarization', with the poorest and most disenfranchised experiencing the highest mortality burden. In addition, South Africa is experiencing a 'prolonged or protracted transition', with partial change in morbidity patterns, in which the stages of epidemiological transition proposed by Omran in the early 1970s, overlap.

This shows the complex picture that forms around the structures and dynamics of healthcare in SA. Khan (2011) notes that the impact of chronic conditions (both communicable and non-infectious), and the associated morbidity and mortality of these conditions, have overburdened an already under-resourced and strained health system. This compromises the ability for the public health sector to deliver quality care and services. Moreover, the historical legacies of apartheid policy, along with their effects on health outcomes for different groups in SA society, contribute to the challenges faced in providing effective and quality healthcare to people living in the country (Wadee et al, 2003).

In discussing the attitudes of health care providers in SA, Gilson (2003) argues that many studies have uncovered the fact that public health care providers are untrusting of their patients, and their motives for seeking help. Gilson (2003) was specifically referring to marginalised groups like foreigners and teenage mothers and was demonstrating this effect in public healthcare settings. The study described in this thesis was focused primarily on a group of patients who exclusively utilised private healthcare in seeking help. Despite this, the experience of being marginalised and disregarded by practitioners who were unsympathetic and uncaring was evident in the narratives of the participants. This suggests that trust is affected by practitioner attitudes, and the status of an illness condition, regardless of whether the interaction takes place in the private or public health care sector (Åsbring and Närvänen, 2004).

Werner and Malterud (2005) illustrate the effect of recognition (a form of belief and trust) on women's experiences of living with fibromyalgia. Werner and Malterud (2005: 41) show "how being met with recognition within group treatment had strengthened the patients' recovery process, described as a contextual, relational, and gendered process of constantly ongoing work, achieving a better life with chronic pain". Gilson (2003: 1461) explains that trust is critical to functioning health systems because "it underpins the co-operation throughout the system that is required for health production… Rather than simply being shaped by the changing basis of societal values, a trusting and trusted health system can contribute to building wider social value and social order". Trust was important for the participants of my study as the condition they lived with was inextricably shrouded in uncertainty, confusion and contestation (Åsbring and Närvänen, 2002). Gilson (2003) asserts that trust between patients, their practitioners and the system they operate within encourages different outcomes on individual, community and societal levels.

Beck (2000) explains that the inequity, lack of resources and issues of access essentially produce two parallel systems of healthcare: one private and one public. While the country experiences the full spectrum of diseases that are found in developed and developing countries, these inequalities between the two systems of healthcare mean that specific illnesses are better addressed in each sector (Beck, 2000). Namane (2013: 380) explains that "most primary healthcare (PHC) workers are not skilled in the diagnosis and management of

musculoskeletal conditions, despite the fact that they amount to 15% of a general practitioner's workload" in SA. Rauf et al (2013) assert that there is very little information available concerning chronic prevalence in SA PHC settings, a problem that reflects the global dearth of research and low priority of the subject.

This negligence occurs despite the profound biopsychosocial impact of chronic pain on the quality of life for the individual, and "significant impact on the utilisation of healthcare services" found in addressing these conditions (Rauf et al, 2013: 85). The ability to access practitioners and facilities in the diagnosis and treatment of chronic pain is affected by the affordability of the process, and limitations imposed by medical aids in SA. As Coovadia et al (2009: 10) explain,

> In 2005, annual expenditure on medical schemes and out-of-pocket payments was approximately R9500 [$1170] per beneficiary. A further 21% of the population use the private sector on an out-of pocket basis mainly for primary level care, but are generally dependent on the public sector for hospital care (expenditure per head R1500 [$185] per person in 2005).

Therefore, at the point of accessing diagnosis and treatment, both the recognition of the conditions and the availability of care granted through costly medical aid schemes need to be accounted for. The lack of recognition could be due to PHC policies that are not geared to promoting awareness of musculoskeletal conditions, and Namane (2013) asserts that in SA, there are currently only 50 registered specialist rheumatologists. Furthermore, given the proportions of patients seen by practitioners at different levels of the healthcare system, there is an implication that "the majority of patients with musculoskeletal disorders are largely seen by an unskilled workforce" (Namane, 2013: 381). Namane (2013) analysed practitioner engagement and consultation outcomes at two community health centres in the Western Cape.

The lack of prioritisation of musculoskeletal conditions and training in practice creates a scenario in public health settings where misdiagnosis and incorrect use of treatments is frequently experienced (Namane, 2013). While this occurs in private health settings too, the

ability and resources available to people using services in that context allows for the further pursuit of care, whereas those accessing public health care must receive what is available. As previously discussed, diagnosis of fibromyalgia takes active searching and multiple consultations to find a practitioner who can recognise the symptoms. In SA, the proportions of facilities, practitioners and specialists available between the public and private sectors will ensure that encountering fibromyalgia as a diagnosis requires high amounts of social and fiscal resources. Access to medical aid (also referred to as healthcare insurance here and in the literature) plays a massive role in coming into contact with the type of practitioners needed in order to diagnose fibromyalgia in this context.

What this explains is a scenario whereby those who can afford private healthcare pursue consultations and treatments from practitioners operating in that sector. This is enabled by the subsidisation of medical insurance schemes that influence the accessibility of healthcare in SA. McIntyre et al (2003: 48) describes how "South Africa has a substantial, and growing, private health sector… [and] the single largest category of financing intermediary in the private sector is that of medical schemes, which are nonprofit associations funded primarily by contributions from employers and employees". McIntyre et al (2003) go on to state that many of the schemes are managed by for-profit administrators and there is a significant government subsidy granted to medical schemes through tax deductions from employer contributions.

These dynamics of distribution are reflected in the sample drawn for this study, since medical aid possession and out-of-pocket payments featured in their illness experience as enabling and limiting factors respectively for receiving treatment and care. Furthermore, people with contested conditions such as fibromyalgia will not find their diagnosis through the ordinary means that most people would when enacting help-seeking behaviour. It takes repeated consultations, and high levels of education to recognise and articulate the problem at hand, and to continue the search in the face of scepticism, disbelief and disregard. In a country like SA where access to practitioners and particularly specialists is tightly controlled and relatively limited, higher levels of social capital and fiscal resources are required to gain consultation and diagnosis of conditions like fibromyalgia, which are characterised by uncertainty (Padarath et al, 2003). This explains the population of people I was able to draw

my sample from, and the demographics that emerged in the group. This is discussed further in the methodology chapter of this thesis.

Fibromyalgia in popular media

An important component that needs unpacking in the contextualisation of fibromyalgia is the predominant perceptions of the condition in popular media. The media as an influential source of knowledge about health and illness played an interesting role in the illness experience of people living with fibromyalgia in SA. In investigating the impact of uncertainty on medical legitimacy and social acceptance in fibromyalgia illness experience, it was important to understand where commonplace ideas of "pain" and "exhaustion" are located. By gaining insight into how popular notions of these symptoms are framed around a person with a chronic condition like fibromyalgia, explanations of the responses of that person as a credible patient can be developed. Furthermore, through this avenue, the abilities of the patient to seek out social support and sympathy for their condition can be viewed. While the internet has enabled people easier access to a variety of health-related information, it has also perpetuated the frequent stereotypes and stigmas associated with chronic condition of uncertain aetiologies like fibromyalgia (Cohen et al, 2011).

The internet (along with other media sources) is a vital component of the process of making sense of the experience of fibromyalgia, both before and after diagnosis as it provides the is opportunity to learn and adapt in light of the information shared on these platforms (Nettleton, 2004b; Lupton, 2013; Tang and Ng, 2006). Additionally, by analysing media content, the trajectory and increasing presence of the label of "fibromyalgia" in health-related information and medical discourse can be seen as it plays out over a period of time, as well as illuminating the type of information mentioned alongside the condition. This also helps in understanding the ‘public’ image of fibromyalgia that, to a certain extent, constitutes the context in which their experiences are formed (King, 1997).

The media sits alongside medical discourse and plays a vital role in the illness experience of conditions that are characterised by contestation, uncertainty and scepticism. This is seen in

people turning away from traditional sources of health knowledge (such as doctors) and towards innovative means of making sense of their experience (such as internet searching) as seen from the interviews in this study (Price and Walker, 2013). While media content was not the focus of this study, it emerged in the course of the research that all the participants engaged in media searching activities at some point in their illness career. The main ways that this behaviour was enacted was through firstly attempting to find explanations for their inexplicable symptoms, which had not been categorised by doctors as medical issues. Media also was present in the processes involved in absorbing the diagnosis of fibromyalgia as something real in their lives, both medically and socially (Lemire et al, 2008). The internet and other media sources were used to explore treatment options and to find commonality in the experience of others who also had fibromyalgia. Additionally, for two of the participants of this study, the media and other knowledge sources, namely peers, enabled them to self-diagnose with fibromyalgia (Barker, 2010). This is explored later in the thesis.

Shifting domains of health, illness and disease

Theoretical perspectives and conceptual definitions

In moving between the domains of health and illness and negotiating through biomedical and social understandings of each, the concepts of 'health', 'illness', 'disease', and 'sickness' require discussion given their central role in this study. Parsonian perspectives of Medical Sociology propagate the notion that medicine is an influential and participative institution in controlling deviance within societies and jars the view that medicine is dormant in this capacity (White, 2002). Although Foucault presents challenges to Parsons eventually, he agrees that the institution of medicine exists as a continual exercise in relations of power and the most concrete form of medical power is the tendency to administer. White (2002) discusses Foucault's view that medical practitioners enable a structure of power by labelling, categorising and prescribing those that are healthy and those that are not.

Furthermore, practitioners determine those that are able to exist freely in society and those who are relegated to the margins if not entirely removed and monitored until an appropriate level of 'wellness' or 'normality' has been achieved and maintained. It is important to

understand the processes, relations and dynamics in the interactions involved in categorising 'sick' people. This should be done in order to explain how people living with a chronic, contested condition like fibromyalgia are restricted or enabled in their pursuits of diagnosis, treatment and health. As this was the primary aim of the study undertaken here, it is necessary to unpack these concepts, before utilising them in the analysis and discussions contained in this thesis.

For Bury (1998) the term ‘health’ has attained particular cultural salience in the increasingly globalised world where being uninvolved in the forces of modernity is evermore impossible. This means that ‘health’ as a concept is being shaped and defined (in part) by the forces of modernity and globalisation. Simultaneously it is being received and utilised in meaningful ways by individuals who have societal and cultural norms and beliefs that impact on their understandings and lived experiences of the term (Bury, 1998). In adopting a holistic perspective for understanding health and illness experiences (as was the central task of this research study), the Psycho-Social-Environmental model discussed by Gilbert, Selikow and Walker (2010) is the most appropriate lens for viewing these complex and interrelated processes. This is because it allows for detailed and inclusive explanations of people’s perceptions and experiences of their health and illness.

‘Illness’, like health, is a socially constructed concept that encompasses the identification and treatment of symptoms that vary in their severity. More broadly speaking, Blaxter (2004) states that this process encompasses recognition of symptoms; the perceived seriousness thereof and the extent to which daily social activities are disrupted by these symptoms. The frequency and persistence of the illness as well various psychosocial stages of illness behaviour, such as family tolerance, denial or fear are also influential. The amount of access to knowledge and information available and the competing and conflicting interpretations of the symptoms are other components included here. Finally, the treatment options available to the individual as well as the affordability and access to them additionally shape this process (Blaxter, 2004). This epitomises the combined Bio-Psycho-Social-Environmental Approach in that symptomatic indicators are the key identifiers that lead to an individual being categorised as “sick”.

Having said this, the responses and reactions to that initial process are heavily social in nature, referring to indicators such as sick-care availability and the ways in which social life is disrupted by the presentation of symptoms (Blaxter, 2004). **'Illness'** constitutes the subjective and individual experience of lost health – thus it has a psychological component. 'Disease', on the other hand, is an objective biomedical label and category used to give a condition legitimacy and recognition. **'Sickness'** is a social concept that refers to the societal component of the experience determined by the 'legitimate label' of the bio-medical practitioner (Gilbert et al, 2010).These definitions relating to the social construction of health and illness were vital for the approach of the study undertaken here. Contested conditions like fibromyalgia are characterised by their complexity. Thus explaining the experience of these conditions in a particular context involved drawing on these concepts and utilising the holistic stance propagated in the biopsychosocial approach.

Explaining narratives of people living with medically ill-defined conditions

The following explanation of narratives and their function in relation to chronic illness presented by Werner et al (2004: 1036), citing Hydén (1997) perfectly captures the objectives of this study,

> The concept of a narrative has been used in a variety of ways and contexts: It can be defined as an entity that is distinguishable from the surrounding discourse and has a beginning, a middle, and an end… The narrative is one of several cultural forms available or formulating experience of illness and suffering. It is also a medium for conveying shared cultural experiences. Narratives have gained importance in the study of chronic illness as a means of understanding the attempts of patients to deal with their life situations and the problems of identity that illness brings with it.

In aiming to understand how an experience of a chronic condition characterised by uncertainty and complexity plays out in a particular context, utilising the perspectives of people who live with this condition became an important tool for gaining unique insight. For Frank (1997: 5) "illness becomes a *circulation of stories*, professional and lay" with inequality existing between the narratives. Biomedical narratives hold the most authority and

power in this circulation. Frank (1997: 5) explains that "the story told by the physician becomes the one against which others are ultimately judged true or false, useful or not". Frank (1997: 5-6) further discusses Parson's notion of the 'sick role' where a "core social expectation of being sick is surrendering oneself to the care of a physician".

Frank (1997: 6) explains that the condition of seeking medical help is a "*narrative surrender*" and can be identified as a "central moment in modernist illness experience". Part of the medical encounter is the implicit agreement to follow the prescribed treatment. Another component of these expectations is that one's experience will be related through a medical framework and discourse as the physician's account of the disease and illness becomes what is repeated by the patient in telling their story (Frank, 1997). Frank (1997: 6) states that "the *postmodern* experience of illness begins when ill people recognize that more is involved in their experiences that the medical story can tell. The loss of a life's map and destination are not medical symptoms".

Importantly, this indicates the biographical layer of illness experience, in that it is a lived process that affects not only one's ability to function in their body but also in their social lives. Fibromyalgia as a medically ill-defined condition becomes a useful lens through which this "*postmodern* experience of illness" that Frank (1997) discusses can be explored and understood. Fibromyalgia and other medically ill-defined conditions fall outside of the conventional boundaries of biomedical explanation and treatment. It involves a realisation on the part of the patient that their experience is still legitimate despite the lack of understanding and care afforded to them. For these reasons, fibromyalgia is an impeccable illustration of a postmodern illness experience and was worth investigating.

This study adopted Nettleton et al's (2004) analysis of Frank's (1995) narratives of illness, namely **restitution, quest and chaos** narratives. This was because the focus of this study speaks to those people who are unable to successfully adhere to a restitution narrative and are then forced into quest and chaos narratives to explain their illness experiences. Nettleton et al (2004) explain that, for Frank (1995), a quest narrative illustrates the individual's belief that venturing further into an illness experience by consulting various healthcare practitioners will

produce something meaningful. Specifically "the illness may become a metaphorical journey from which the ill person may gain self-awareness, or the ability to help others" (Nettleton et al, 2004: 50). The chaos narrative, as the next stage in an illness experience, emerges when there is no clear plot or structure that can be used to understand an individual's encounter with a condition. The person's narrative cannot follow the format of a "journey" as the beginning, direction and conclusion is unknown and unclear (Nettleton et al, 2004). The research undertaken here investigated the extent to which people living with medically ill-defined conditions such as fibromyalgia utilise restitution, quest and chaos narratives in explaining their illness experiences.

Lonardi (2007: 1619) discusses the "socially invisible" nature of chronic headaches as a disease and explains the interaction between the "objective (disease), subjective (illness), and social (sickness) aspects of [patients'] condition" in understanding biographical disruption and illness experience. Following Bury (1982), Lonardi (2007: 1621) explains that biographical disruption encompasses the process through which disease alters and affects daily social life permeating through individual identity, function, capability and social relationships. This relates back to Frank's (1997) notion of illness narratives and the ways in which patients' stories are moulded into medical accounts. With conditions such as fibromyalgia, there is no related definitive cause or consequence. Furthermore, the lack of clinical evidence displayed in the person's body of organic, objective disease calls into question both the legitimacy of their symptoms as well as their identity as a sick or healthy person.

On the treatment end of the experience, there are a variety of options offered for fibromyalgia, many of which correlate with standard pain management techniques and medicines. The range of choices that can be made in relation to treatment further complicates the ability of the practitioner to prescribe and the patient to recover, as the focus is on symptom alleviation and management of the condition (Arnold, 2010). Within this interaction around treatment, people with fibromyalgia draw on chaos rather restitution narratives to explain their experiences. This is because hope for resolution of their illness does not exist within these contested, chronic conditions. Viewing this complicated and fraught picture was a core objective of the study undertaken here.

Contested conditions and medical legitimacy

The study detailed herein aimed to investigate the ways in which diagnosis and treatment available for a medically ill-defined condition shape the behaviour and beliefs of a patient in their illness experience. Barker (2011: 833) explains that in the context of contested illnesses, pharmaceutical companies, government, insurance companies, advocacy groups and individuals are able to utilise "pharmaceutical determinism [...] in promoting and legitimizing contested diagnoses and validating those who are so diagnosed". For Barker (2011: 833) pharmaceutical determinism is "the cultural logic whereby the existence (and marketing) of an officially approved prescription medication for a condition lends support to the biomedical existence of the condition itself". This illustrates the importance of understanding processes of diagnosis and, by association, prognosis and treatment.

Furthermore, it was useful to investigate which key stakeholders and role-players constitute the environment in which people living with fibromyalgia, and other medically ill-defined conditions, are able to make sense of their illness experience. Additionally, it highlights the potency of diagnosis and treatment in continually legitimizing and delegitimizing people living with medically ill-defined conditions. Another strand of investigation and analysis utilised here relates to the ways that a lack of clear prognosis contributes to scepticism and confusion surrounding fibromyalgia patients in adapting their lives around their condition.

The treatment of symptoms rather than the cause of an illness characterises many elusive chronic medical conditions including fibromyalgia. Additionally the confusing and contested body of knowledge that exist around the condition further fuels the uncertainty that people diagnosed with fibromyalgia are faced with. According to Sim and Madden (2008), while fibromyalgia syndrome (FMS) has been recognised as a clinical syndrome for over 30 years, the legitimacy of the disease is still heavily contested and debated within medical circles. Sim and Madden (2008: 57), citing Raspe & Croft (1995), state that FMS is portrayed in terms of "four cardinal features: chronic widespread pain, sleep disturbance, fatigue, and bilateral tender points". Sim and Madden (2008) locate the ambiguity of FMS and its legitimacy in the ambivalent diagnostic criteria. Additionally, there is a failure on the part of

the medical sciences to clearly identify the aetiology of the condition or to provide any curative, effective treatment. Sim and Madden (2008: 57) state that identifying FMS in a patient occurs as a “diagnosis of exclusion” and as the diagnosis is a contested one, there are “consequent difficulties for the patients at the level of their interaction with health professionals and their subjective experience of symptoms”.

For Cooper (2002), the questioned legitimacy of illnesses that have no organic disease basis creates a conflicted relationship between health care practitioners and patients. Specifically in relation to syndromes (such as migraines and FMS, and in his work on chronic fatigue syndrome), the absence of biological or visible illness leads to patients’ symptoms being “dismissed and disbelieved” (Cooper, 2002: 181). In the face of this ambivalence patients no longer act as “passive agents when their needs were not met, [and they] actively pursued their own paths to knowledge and challenged the authority and status of their GPs [general practitioners] and consultants" (Cooper, 2002: 181). As Barker (2008: 23) notes, "in the case of many contested illnesses… sufferers are steadfastly committed to framing their problems in biomedical terms". This links back to Nettleton et al’s (2004) utilisation of Frank’s (1995) notion of quest narratives. It highlights a crucial point in relation to medically ill-defined conditions in that patients do not stop searching for effective diagnoses, treatment and care even when the medical sciences are unable to adequately explain their health status. It also speaks to the intricate relationship between perceived physical health and social ability.

Sim and Madden (2008: 58), following Dingwall (1976) and Goffman (1968), explain that with chronic illness, a disruption occurs in “the assumptions of ‘ordinariness’ and ‘normality’ that underlie social interaction [...] calling into question social competence and, on occasions, giving rise to imputations of moral deficiency”. Cooper’s (2002) account of how patients continue in their attempts to gain legitimacy for their illness is underscored by Sim and Madden’s (2008) argument. This shows that in order to attain credibility in themselves and their experience, people with contested conditions must remain within a state medical service and system. The relationship between medical power and broader social control in determining what qualifies as 'normal', 'healthy', 'legitimate' and 'recognised' is thus highlighted.

Cooper (2002: 185) explains this clearly in saying that "attempts to attain legitimacy [for the patients' symptoms and illness] took on a moral face as the patients took pains to show that they were really ill and 'good' or 'normal' patients: that they themselves were not deviant although they might have a 'deviant' illness". They were also at pains to show that they were doing their best to return to a positive state of health. Dumit's (2006: 578) analyses CFS[2] and MCS[3] (as medically ill-defined conditions, similar to fibromyalgia) and shows they are "serious, fraught conditions not only for the persons afflicted, but also for the thousands of physicians, families, researchers, corporations, insurance and administrative agencies having to deal with them". This assessment adds another layer to Cooper's (2002) discussion of the interactions and structures involved in patients' attempts to gain legitimacy for their illness experience.

The complexity of diagnosis

MUS and fibromyalgia

The condition discussed under the banner of "medically unexplained symptoms" (MUS) in this study is **fibromyalgia**. Other conditions that are commonly grouped alongside fibromyalgia within MUS include migraines, IBS and CFS. The term draws on Nettleton's (2006a) phrase, which refers to conditions, illnesses, and symptoms where a clinical diagnosis and biomedical explanation of the person's experience is elusive and often unattainable. Studies investigating MUS often problematize the monolithic structure and character of diagnosis as a labelling and organising mechanism. This is shown in the case of fibromyalgia, because in its manifestation and aetiology, the label neatly fits within MUS by having aspects that are poorly recognised by biomedicine (Mik-Meyer and Obling, 2012). Having said this, fibromyalgia is distinguished from the grouping of MUS insofar as there is a moderately accepted clinical diagnosis attached to the symptoms experienced within the condition. Furthermore, access to healthcare, while disparate and often ineffective, does occur.

[2] Chronic Fatigue Syndrome
[3] Multiple Chemical Sensitivity

As fibromyalgia is often studied under the field of MUS, it is important to discuss the concept further. The term refers to a broad category of conditions, illnesses and symptoms, which are recognised by the biomedical field and so diagnosis, and entry into a Parsonian notion of a 'sick role' is possible. However, no organic or biological cause can be found for the condition and as a result, any treatment available is ineffective in “curing” the patient and returning them to a positive state of health. There is adequate recognition of the condition for diagnosis to occur, however this is not enough. Contestation over the existence of the condition is rampant given the uncertainty surrounding the causes of the illness and the range of appropriate and effective treatments that could be available to address the condition. The capacity to recognise symptoms as illness is dependent on the context, the medical discourse, practitioners and health services available as well as lay cultural knowledge circulating in the society the individual lives in. This leaves people living with these conditions hovering “precariously in a void between illness and disease” (Nettleton et al, 2004: 47) with little prospect of emerging from the confusion into a state of improved health and 'normality'.

Exploring the experience of contested conditions through the narratives offered by those living with fibromyalgia in the SA context was a useful way to capture and explain these "voids". For Greco (2012), the category of MUS introduces both useful and conflicting elements to medical encounters and patient experience. MUS as an umbrella term (which includes fibromyalgia as well as a number of other conditions) has played a facilitative role in grouping together people who are unable to successfully find explanation, and often relief, within current biomedical knowledge and practice. This contributes to the statistic offered by Jutel (2010: 231) where she reports that between "10 to 35 per cent of primary consultations fail to alleviate the presenting complaint". This in turn frustrates practitioners, distresses patients and results in higher expenditure and consultation with healthcare systems in searching for an answer. This forms part of consumer-driven medicalization, an essential component of which is the reification of the disease label of fibromyalgia (Barker, 2008). For Barker (2008: 27), collective confirmation of the existence and objective status of fibromyalgia is what gives the label its meaning, and in the absence of this, "the certainty that underlies lay expertise and compels the consumers to seek medical recognition and treatment would be lacking".

This highlights the relevance of investigating conditions such as fibromyalgia that fall into the ambiguous gaps between patient experience and medical expertise. It also importantly speaks to the inherent and perpetuating conflict between those who are ill and their healthcare providers. Greco (2012: 2365) explains that the term MUS invokes a particular set of relations and expectations that can simultaneously assist and restrict an individual or groups ability to navigate through an illness experience, insofar as MUS is "associated with illness that remains undiagnosed". There are also many theoretical and clinical explanations surrounding the causes of fibromyalgia, which complicate the question of what is "unexplained" in the condition to qualify its inclusion in MUS.

It is argued here that fibromyalgia as a label illuminates and legitimises particular experiences of exhaustion and pain when the diagnosis is received. However, the deficiencies found in established causes and associated treatments that provide relief mean that there are many components of fibromyalgia that remain without answers, or are left "unexplained". According to Barker (2010: 158), contested illnesses are "social constructions that give biomedical meaning to a broad range of distress and suffering that characterize the lives of many individuals, especially women. The contested status of these diagnoses, however, signifies only partial medicalization". This is explored later on in this thesis, particularly in relation to the effects of this chaotic process on knowledge seeking, development of coping strategies and perceptions of healthcare practitioners. It is also important to note that many chronic illnesses contain challenging elements that confound biomedical knowledge and practice. Therefore, both in terms of falling within the categories of MUS and chronic illness, fibromyalgia experiences reflect these processes and provide a useful and enlightening case to study.

Diagnosis has a deeply rooted place in the experience of illness, as a momentary or continuous event (Price and Walker, 2013; Mik-Meyer and Obling, 2012). The event affords access and meaning to a person whose symptoms are deemed as abnormal by themselves and their society (Dommerholt and Issa, 2010). The centrality of biomedicine in society is evident in diagnostic procedures, with medical skill, knowledge, techniques and technologies being privileged as the means through which a patient, their symptoms and experience are validated (Jutel and Nettleton, 2011). The dominance of biomedicine carries over into the institutional

and social interactions people have as a result of being ill. Biomedicine affords legitimacy, and in maintaining its position, alternative explanations and treatments (particularly those found outside of the biomedical realm) are met with suspicion and outright disregard (Madden and Sim, 2006).

This is relevant in terms of the context of SA, where the reliance on private medical aid to provide and supplement access to health care services shapes help-seeking behaviours in tangible ways. Furthermore, for people involved in the study detailed here, the status and nature of the diagnosis of fibromyalgia has real impacts on their abilities to make meaning and sense of their illness. It also affects their ability to articulate it to others and to receive medical and social support (Skuladottir and Halldorsdottir, 2011; Barker, 2011; Werner and Malterud, 2003). Gaining access to practitioners and treatments is determined by the possession of a recognised diagnosis and the presence of practitioners who are accepting of that diagnosis in the healthcare environment and culture (Werner et al, 2003). Diagnosis as an event is evidently important, as it is a crucial turning point in illness careers. Confusion and searching dominates narratives beforehand and shifts occur in the direction the patient will pursue following that event.

Associated with these labels are various social roles and actors, which give insight to the overall workings of a society and the inequalities in status, position, resources, power and authority that shape the individuals' health and illness experiences. For instance, Sim and Madden (2008: 59) discuss the notion of an **"illness career"** which refers to the role a person adopts when they experience a change in their health status. The concept also refers to the norms, values, expectations and behaviours that are associated with that particular identity. Sim and Madden (2008: 59) describe an illness career as "the longitudinal course of an individual's experience of illness and the various stages- conceptually distinct but often temporally overlapping- through which he or she may pass". Their study investigated the roles of the dynamics of health professional interactions, and the attached meanings, in shaping illness experiences. They also viewed the influential components of gender in both interaction and experience (Sim and Madden, 2008).

The inclusion of gender in this regard is expected, given the aforementioned gender incidence disparity between men and women who experience fibromyalgia. This additionally highlights the complex nature of illness experience as it is subject to various political, economic, cultural and social forces with many actors, institutions and factors involved in the process (Dumit, 2006). The neutrality and embracing nature of the label of MUS is helpful for patients, in that they are about to recognise their symptoms as illness and their experiences as valid. However, MUS "is not itself a diagnosis but rather a diagnostic no man's land; it does not perform any of the positive functions diagnoses are meant to perform, namely to explain, legitimate and normalise" (Greco, 2012: 2365).

An additional layer of complexity found with a condition like fibromyalgia is the location of the label in the medical hierarchy of diagnoses. The condition has a relatively low prestige due to the vague and contested explanations that follow the label (Album and Westin, 2008). Nettleton et al (2004: 48) show that illnesses which "are not defined in terms of organic pathology but on the bases of their symptoms are almost invariably 'contentious conditions'". Werner et al (2003: 496) explored the impacts on experience in a treatment programme for women with musculoskeletal pain and found that among their study population, "being met with a recognizing attitude… had enhanced various aspects of strength, confidence, and awareness, which appeared as an increased bodily, emotional, and social competence". This important point is utilised later in this thesis, particularly in terms of the typology of competence presented above. Here, however, the focus is on the supportive environment and qualitative difference in experience established by a recognizing attitude when addressing chronic musculoskeletal pain (which is a distinguishing feature of fibromyalgia).

Werner et al (2003) stated that the competence discovered in their treatment sessions carried applicability for the people involved outside of the programme. This was because they could access "different tools for dealing with a painful life and various aspects of the subsequent sick role" more readily and cope with components of their illness effectively (Werner et al, 2003: 496). Furthermore, a divergence appears with the experience of illness and concocted "'genuine disease'… [where] something of a hierarchy between the 'medically explained' and 'medically unexplained symptoms' (MUS)" emerges (Nettleton et al, 2004: 48). Gaining innovative perspectives on the challenges of addressing these divergences in the course of the

illness career of fibromyalgia patients was achieved through an exploration of narratives of those living with condition, and is explained throughout this thesis.

Diagnosis as label and category

When viewing conditions that confound medical explanation, the diagnostic process of determining what is amiss becomes challenging for the patient, the practitioner, the health system they interact with, and the society they belong to. As Jutel (2010) explains, the distinction between illness and disease is central in diagnosing a condition and moving symptoms from personal experience into the medical encounter. Jutel (2010: 231) argues that "illness is the undesirable change in social or personal function that the individual brings to the medical consultation in search of a remedy. Disease, on the other hand, is medicine's categorisation of illness: a biological or psychophysiological dysfunction or mal-adaption". Illness is individually felt and experienced in the cultural interpretation of pain, exhaustion and discomfort as problematic and in need of intervention (Lupton, 2003). Disease, having sought consultation with a health-care practitioner, is discovered and dispensed as an explanation for illness under the new guise of medical diagnosis.

Jutel (2010: 231) further emphasises the crucial distinction between illness and disease in stating that "disease labels enable access to services and status that are not otherwise available". Medical diagnosis, in its form and mechanism, is meant to provide explanations of the symptoms, causes, expectations and treatments associated with an illness. In doing so diagnosis gives meaning to an experience, clarity on why it is happening, and what can be done to overcome it. With conditions like fibromyalgia, the categorisation of the experience as an illness is achieved in ascribing the medical label that allows the pain and exhaustion felt by the individual to be recognised and made distinct from other forms of discomfort (Dommerholt and Issa, 2010). However, there is a lack of visible biomedical indicators to diagnose the condition, and the complex nature of the illness that produces a murky prognosis.

There is also a multitude of treatment options available, and all this renders the condition's status in the diagnostic hierarchy as marginal, vague and suspect (Werner et al, 2003). Greco (2012: 2363) explains the "importance of valid diagnosis for legitimating illness" either at an experiential level or within the realm of legal frameworks, insurance schemes or welfare benefit. As Jutel (2010: 234) explains, diagnoses "are not only the classification tools of medicine, but also the means by which medicine does its work. As an act of classification, diagnosis is organisational, informational and embedded in practice". She goes on to state that diagnosis has the potency and valorising capacity of all classifications, in that it brings some perspectives into view while shielding others (Jutel, 2010).

Diagnosis as process

Greco (2012) further shows the complexity and contradictions of the label of MUS in that it denotes and reinforces an expectation surrounding the "unexplained" elements of the symptoms. Specifically Greco (2012: 2365) states there is an implication that "with sufficient investment and research, a biomedical cause will be found" to account for the currently elusive and confounding symptoms being experienced. This critique is important and shows the complexity inherent in diagnosis. A label not only names, but also describes, allocates expectation and resources, directs behaviour response and action, and affords access to treatment otherwise unavailable. Importantly for those interacting with private medical insurance and care in the SA context, the legitimacy and recognition dispensed with a diagnosis contributes to what healthcare services can be utilised. Furthermore, it determines whether treatments are financially covered by the medical aid scheme and for how long, as has been shown in this study.

De Ruddere et al (2012) discuss the fact that for many people, biomedical causes constitute the gold standard and only explanation for illness. Pain is seen as a manifestation of physical pathology, but it is very common for that pain to be inexplicable in its aetiologies. De Ruddere et al (2012) explain that the represented struggle, which is felt by those living with and treating pain, emanates from an insufficient medical explanation. Specifically De Ruddere et al (2012: 1198) argue that people living with inexplicable pain "may feel disbelieved, misunderstood, or unaccepted by others" including healthcare practitioners who

in turn question how credible the presented symptoms are. Furthermore, those practitioners may feel impotent in their care-giving abilities. MUS, in Greco's (2012) view, enables support for people and their symptoms who cannot find cause nor comfort in the traditional biomedical sphere of healthcare.

Simultaneously, MUS challenges the tenants of the discipline to go beyond objective, visible, biomedical markers to indicate the presence of illness in the body. However, despite the guise of neutrality, MUS also demands of patients and practitioners an adherence to those same expectations and explanatory models that it is attempting to challenge. MUS is collective and embracing in its form and it acknowledges the limitations of medical knowledge and practice. Despite this, it still expects biomedicine to provide concrete answers, to give causal explanations, and in turn resolve illness and provide relief for patients. It is with this last point that Greco (2012) argues particularly strongly; there is contradiction in a classification which inevitably functions the same as other disease categories in seeking solace and care in biomedicine. There is a tension related to the functionality of MUS in holding it to standards beyond its capacity, while accounting for shortfalls, and criticising both the approach and practitioners who use it for not providing enough knowledge and support (Greco, 2012).

As a subcategory of MUS, fibromyalgia presents a significant case study in that it provides a lens through which these broader political, theoretical and social processes can be viewed in tangible and impactful terms. The study undertaken here was able to capture the complexity of a diagnosis that reflects the precarious position of MUS while also allowing people legitimacy and credibility for their illness experience. Fibromyalgia and other conditions that fall within MUS are different from general diagnoses, partly because of the lack of knowledge, legitimacy and biomedical identification associated with the symptoms and illnesses experienced. The distinction takes the form of the known causes, expectations, trajectories and treatments as well as the curable rather than chronic nature of the illness.

As Greco (2012) argues, implicit in the label of MUS is a difficulty faced by biomedicine, practitioners of the discipline and the knowledge they draw on. The challenge takes the form of symptoms that confound medical explanation and patients whose complaints and

conditions are inadequately addressed within biomedical practice. The impacts are individually felt; more so than with conditions that have high biomedical recognition. Fibromyalgia defies convention, providing challenge and query at every turn of the illness experience. For these reasons, it is included in the collective experiences, symptoms and conditions that are attached to MUS as a label and field of study. The research detailed in this thesis showed that people with fibromyalgia in SA face continual scepticism because of the uncertainty that characterises their experience.

In externalising knowledge, cost, investigations and outcomes away from the medical realm, understanding the processes involved and the mechanisms and narratives drawn on by patients to navigate through their illness experience becomes relevant and important as a site of study. Greco (2012: 2365) succinctly notes that the problems experienced in attaining diagnosis, as well as the tensions apparent in offering care and effective treatment, render the category of symptoms and attached patients found under the label of MUS as a '"difficult truth"'. The recognition and credibility of a diagnosis is afforded by the ability to easily detect a pathogen or disease, using biomedical indicators and explanations of what is happening within the framework of biomedical knowledge (Gardner et al, 2011).

This process places illnesses at different levels within a hierarchy. The capacity to account for and predict what will occur following diagnosis allows illnesses with these features to find a better position than the ones lack those characteristics (Cöster et al, 2008). Disease categories have a common meaning and recognisable experience. As they have a standardised route and resolution, this enables both practitioners and patients to access a discourse and enact behaviour that is regulated, familiar and expected. As Werner et al, (2003: 503) citing Album (2001) explain, "fibromyalgia is a condition found to have low prestige in the cultural medical hierarchy of diseases" as it contradicts so many of the normal trajectories and expectations associated with most recognisable illnesses.

Diagnosis, medical legitimation and uncertainty

With conditions that lack sufficient medical explanation (like fibromyalgia), the capacity to follow a known path is severely reduced. This creates more space for confusion, delegitimation and chaos to creep in, a point highlighted frequently in the interviews conducted with my participants. The study undertaken here was able to capture both the "chaos" of fibromyalgia illness experience, and the routes and interactions that enable people with the condition to manage and move through it. Kirmayer et al (2004) notes that symptoms without a definitive medical diagnosis frequently appear in all areas of primary and speciality care. This "lack of explanation reflects the limits of medical knowledge, available technology, and the epistemological difficulties of assigning a clear cause to subjective complaints like pain and fatigue, which may have no objectively measureable correlates and may change rapidly over time and in quality and intensity" (Kirmayer et al, 2004: 663).

In characterising the collection of symptoms, illnesses and experiences categorised with MUS, Kirmayer et al (2004) usefully shows the complexity associated with conditions that medicine struggles to account for. These symptoms cannot be easily "seen" medically, on tests, through the instruments and explanations available in biomedical practice. This particularly drives the insistence for credible assessment and reliable articulation from the practitioner and patient to make sense of the experience. There is limited knowledge available, specifically in SA, about how people with these conditions are enabled or restricted in their capacity to discover the explanations and means of managing their symptoms. The research undertaken in this study investigated these processes through the narratives of people living with fibromyalgia in this context. In revealing the diversity of experience and multiple means of attaining diagnosis and responding to fibromyalgia, this study was able to clarify an area of patient experience that is often obscured from sociological view.

Fibromyalgia and other MUS are often invisible on the body, in society and within medical knowledge and practice (Jutel, 2010). Thus, uncovering root causes, and then attaching adequate and relieving treatments to them, becomes an arduous task for biomedicine,

practitioners, health services, patients and the people that support and surround them (Sim and Madden, 2008). Another key feature that marks fibromyalgia as exceptional rather than routine is the *flexibility* required. This was particularly highlighted through this study as the narratives showed that a component of successfully living with fibromyalgia involved reflexivity on the part of the patient and responsiveness from the institutions, practitioners and people who could offer support. Flexibility is required in three ways; in conceptualising what the symptoms, as a collection, mean; in responding to them effectively; and finally in predicting the trajectory of condition - a point that is demonstrated continuously throughout this thesis (Deale and Wessely, 2001; Dumit, 2006; Glenton, 2003). Fibromyalgia as a label is partially effective in gaining access to basic medical care and some support and treatment.

These contradictions make responses become less effective when multiple aspects are elusive and subjective, as is the case with fibromyalgia. This relates to the fact that there are many unaccountable elements fibromyalgia, in terms of both treatments, and how to care for the person medically and socially. Åsbring and Närvänen (2003) discuss the partially overlapping nature of the symptoms of CFS and fibromyalgia that enables the conditions to be analysed together in assessing practitioner descriptions and responses in their study. The overlap also refers to the utility of using an encompassing label like MUS, where conditions and diagnoses that have similar features and effects in illness experience can be discussed collectively. Åsbring and Närvänen (2003: 711) assert that "CFS and fibromyalgia are distinguished by great uncertainty regarding aetiology, diagnostics, treatment and prognosis".

The continuous debate that surrounds CFS, fibromyalgia and other MUS reflects the broader contentions that exist with conditions that are not imbued with biomedical clarity. Specifically these are conditions that rely on criteria diagnoses, subjective telling of symptoms and practitioner buy-in (Åsbring and Närvänen, 2003). As Greco (2012), citing Fink et al (2005), notes MUS refers to those conditions, bodily and medical experiences, and patients who fail to fit neatly within clinical parameters and measures. The symptoms are not easily linked to diseases that would appear conventionally in healthcare.

MUS usefully "covers a wide spectrum of severity, from mild discomfort that many people accept as a normal part of living, to 'clinically significant' symptoms that may involve intense pain and serious impairment, often lasting many years" (Greco, 2012: 2362). The issue of **symptom severity** is comprehensively captured in the experience of fibromyalgia, as symptoms appear to varying degrees at different points in time. While a pattern can be recognised, predicting their onset and duration is fruitless as an activity and leads to much frustration for people with the condition. Additionally the fact elements of the condition appear in everyday experience, namely exhaustion and pain, means there is simultaneously acceptance and scepticism (Cunningham and Jillings, 2006; Barker, 2008). People are able to relate to feeling sore and tired, but cannot comprehend the overwhelming and enduring nature of fibromyalgia pain and exhaustion. This was evidenced in the narratives collected for this study and therefore a contribution is made in understanding the complexity of fibromyalgia experience and the ways that symptom fluctuation creates uncertainty in parameters and responses for the condition.

The inability to find "objective 'truths'", which are normally preferred to patient narrative in biomedical practice, creates an overall sense of ambivalence from biomedicine about fibromyalgia, despite the fact that it has a long established criteria diagnosis (Sim and Madden, 2008; Stockl, 2007). This means that the diagnosis (along with other MUS) has "been subject to various interpretations that have shifted during the years. In particular, there is an ongoing debate as to whether the illnesses are organic, sociocultural phenomena or psychiatric disorders" (Åsbring and Närvänen, 2003: 712). The separations between these components and contributing elements of illness show an adherence of the debate to a biomedical approach understanding of this issue. This is seen through the fact that organic, sociocultural and psychological factors are not seen as interrelated.

As Walker et al (2004) explain, treating fibromyalgia, and other chronic pain conditions, and coping with the illness experience entails locating the condition firmly in a holistic and biopsychosocial approach. This allows connected and disparate causes and outcomes to be viewed together and addressed comprehensively. The ambivalence and disconnect in practitioner approach in turn means that people with fibromyalgia have to articulate their experience as exceptional, real and urgent. It also meant that at the point of seeking a

diagnosis, they are often living with severe symptoms that require urgent attention and intervention (Werner et al, 2003; Richardson, 2005). This process is described in closer detail later in this chapter. Interestingly, as is the case with many chronic illnesses, once the condition has been normalised into a person's life, routes for response to the onset of worsening states of health are impacted and changed as a result. Understanding the "normalised" experience of fibromyalgia and the mechanisms used to manage the condition was a central component of the research explored in this thesis.

Explaining the inexplicable

Citing Malterud (2000) and Steihaug (2005), Råheim and Håland (2006: 741) explain that fibromyalgia cannot be called a disease, but is rather referred to as an "undefined or unexplained disorder". This highlights the complexity of medical diagnosis and the expectation that a medical label is sufficient in explaining what is wrong within the body, as well as what can be done to alleviate the symptoms. In fact, the stage of diagnosis is pre-empted by a host of social and cultural processes tied to symptom recognition, healthcare and practitioner access, and beliefs about health and illness (Blaxter, 2004). These processes play out in a context that variously assists or inhibits the ability of the individual to seek help and experience care and relief. Receiving a diagnosis is only a part of the illness experience and it cannot always account for the extent or complexity of the condition it aims to describe and explain (Jutel and Nettleton, 2011).

This section will discuss the functions of fibromyalgia as a diagnostic label, and explore the partial legitimacy it affords to those living with the condition. For Råheim and Håland (2006), pain is an essential, ubiquitous part of human life. Pain is constituted in the "interplay of existential, social, cultural and bodily processes [and] is a challenge to understand" (Råheim and Håland, 2006: 741). They usefully explain that all pain, especially that which is chronic in nature, is poorly understood by medicine. This worsens in the case of those conditions that fail to fall within the categories and criteria of distinct medical entities.

Multiplicity and complexity as features of fibromyalgia

Fibromyalgia presents an interesting and complicated challenge to the expectation that medical diagnosis straightforwardly grants entry into the 'sick role' for the individual, and offers paths to follow in terms of prognosis and treatment recommendation. This is because fibromyalgia is a condition characterised by multiplicity and complexity with a vague aetiology that cannot be viewed using only biomedical indicators (Koch, 2012). Rather it relies on the subjective articulation from the patient, that what they are experiencing is urgent, severe and in need of attention and care. As Wolfe et al (2011: 297) note, "fibromyalgia diagnosis is based entirely on patient self-report, and there is evidence that fibromyalgia [patients], taken as a whole, are more likely to report symptoms and events, and to rate symptoms and events as more severe compared to persons without fibromyalgia".

Added to this are the skills of the practitioner in correctly identifying and diagnosing the symptoms under the banner of fibromyalgia, while understanding and explaining that causes are diverse, and largely unknown (Kalla, 2011). This means that a label is offered and meaning is given to the patient's experience. However, it does not go far enough in allowing the patient to know what to expect in terms of the condition's trajectory and where relief from the symptoms can be found. While there is an established canon of fibromyalgia treatment (such as prescribing exercise, routine sleep and alleviation of generalised pain symptoms), the overall stance is experimental. A "one-size-fits-all" approach rarely works with fibromyalgia patients (Raff et al, 2014).

As with other medically ill-defined conditions, fibromyalgia sits at the border of recognition and disregard within medical discourse and practice. This is because the symptoms have been grouped under a medical label, but it is insufficient, as it does not offer full explanation of the causes and associated expectations in terms of prognosis and treatment. Citing Barker (2005), Burke and Valerus (2008: 202) discuss the divergences that exist between patients and their practitioners in explaining women's experiences of fibromyalgia and note the following: "patients tend to define fibromyalgia as a disease, but physicians may not; patients assert that tender points are objective evidence of diagnosis, but physicians may not; patients tend to favor organic explanations, but physicians may hold to psychosomatic causes". The power of diagnosis is such that it can transform symptoms into a disease and give meaning and grounding to experiences. Diagnosis potently encourages or disallows the individual to be

sick and receive care, sympathy and empathy as they readjust to an altered state of life (Barker, 2005).

For Jutel and Nettleton (2011: 794), citing Balint (1964) and Frank (1995), the process of diagnosis "organises disease, providing a name, a treatment, a direction to an ailment… [It also] can be a narrative surrender, where a lay person's story of embodied experience is reappropriated and recast by medicine… [or it] is a starting point, the foundation from which sense-making and experiences are crafted". Therefore understanding the ability of fibromyalgia as a medical diagnosis to simultaneously explain and confuse the experience becomes paramount for informing both patient narrative and practitioner interaction. As Råheim and Håland (2006: 756) assert, fibromyalgia "challenges physicians and other health workers to transcend a biomedical perspective that might give narrow and partly misleading definitions".

This holds true for pain generally and chronic experiences of it especially. In the narratives of the people interviewed in my study, the quest for understanding was overwhelming in its presence, both within doctors' offices and afterwards too. Participants could get a name for their condition, but they were then let down in terms of explanations of cause, treatment, prognosis, care or all of it. This is partly because there is not enough known about fibromyalgia, and because it presents in so many forms (Stockl, 2007). There are unpredictable manifestations, which are difficult to capture through biomedical indicators, and this therefore limits the ability of medicine to investigate and offer possible explanations. It is an *inexplicable* condition because many of the expected, usual frameworks associated with medical understanding and every day, relatable explanations are absent in this experience.

Double delegitimation and unpredictable symptoms

Richardson (2005: 36) citing Honkasalo (2001) discusses the fact that chronic pain is often invisible (socially and medically) and also contains the ambiguity associated with chronic illness. This means that chronic pain goes through a process of "double delegitimation" where the normative signs and paths used to determine what is happening cannot be drawn on. The multiplicity and obscurity of the explanations means that the exact character of the pain being

experienced is not easily understood. Richardson (2005: 36) explains that in the case of chronic pain, double delegitimation "may be further exacerbated due to its unpredictable nature. This unpredictability may manifest itself in the body, whereby sufferers do not know from day-to-day where the pain will appear".

This lends support to the argument that prognosis is critical for legitimacy and credibility in illness experience. It is important for moving the person to a patient and allowing forthcoming access for that individual to the 'sick role', and the associated practitioners and treatments. With chronic pain, there is variability in the frequency of pain and the severity of it, which makes it harder to sufficiently capture and explain, as well as predict when symptoms might occur and what can be done to overcome them (Richardson, 2005). Richardson (2005) also usefully explains the complexity presented in the internal, subjective experience of pain where there is little outward sign that the person is going through anything, and the body is largely unmarked. In this scenario, the appearance of pain is indistinguishable from normality.

Ambiguity and uncertainty are common features of chronic illness and in the case of chronic pain; the overall difficulty is escalated by the inability to know how the body will manifest the symptoms of the conditions (Stockl, 2007; Price and Walker, 2013). Furthermore, this creates challenges for the individual in knowing what is causing the pain, what to do about it and what it might mean. Most chronic pain does not show on the body and it is invisible in medical testing and practice. Diagnosis cannot adequately afford knowledge of prognosis and treatment (as is the case with fibromyalgia) and this means that the capacity for credibility and legitimacy in experiencing chronic pain is severely undermined.

Richardson (2005) also discusses the contested nature of pain that is extraordinary, pain that is chronic, and pain that is an illness. She identifies the commonality of pain experience in everyday life as a cause of this strife. This means that symptoms are, to a lesser extent, felt and discussed in the general population but not converted into illness or disease, as is the case with people who encounter chronic, severe and debilitating pain (Barker, 2008). Following Bury (1991) and Ware (1999), Richardson (2005: 45) explains that this is a problematic form of legitimization and that "the everyday nature of the symptoms [in contested conditions] may exacerbate the disconfirming responses when suffers attempt to communicate the nature of their distress".

The trivialising of symptoms such as pain and exhaustion- both strong features of fibromyalgia- which are also commonly felt in the general population leads to a further loss of legitimacy. It also creates increased contestation when communicating the experience as medically and socially real. This is because there is heavy reliance on the patients' ability to tell what is happening, articulately and convincingly, and in ways that distinguish their story as "extraordinary" (Richardson, 2005). For the participants of my study, the capacity to convey the persistence and severity of their symptoms was a continual challenge and resulted in feelings of scepticism and rejection for their experience.

Richardson (2005) delineates chronic pain from chronic illness, while noting that the former has often been subsumed within the study of the latter. For Richardson (2005), the fact that diagnostic labels do not legitimate chronic pain (as well as the invisible, ordinary and subjective character of the condition) means that it is different to chronic illness. Fibromyalgia as a chronic illness condition challenges this idea, because a diagnostic label exists to explain the collection of symptoms. The label gives meaning and support to those going through the experience; however, this legitimacy is fragile and unstable. This insecurity could emanate from the status of the label in the broader diagnostic hierarchy.

Additionally, it could be because of the reliance on patient expertise and narrative (rather than biomedical knowledge) to explain the features of the condition (Werner et al, 2003). The study detailed in this thesis was able to illustrate, in the emergent findings, the effect of partial legitimation and the consequences for beliefs and behaviours surrounding the illness experience of fibromyalgia as told by those living with the condition. People with fibromyalgia in the SA context are able to access the diagnosis, but then face complication, challenge and ambivalence as the prognosis for the condition is not forthcoming in interactions with practitioners and health systems. This affects the ability of the person with fibromyalgia to navigate through their illness experience unabated by discrediting perceptions from their support networks, which makes living with the condition even more challenging (Stockl, 2007; Barker, 2011).

Illumination and concealment- fibromyalgia as a diagnostic label

While fibromyalgia has a diagnostic label, established criteria and testing mechanisms as well as recommended treatments, the heterogeneous character of the condition makes it difficult to concretely explain the causes of the symptoms. Additionally, it is difficult to predict the manner in which the condition will play out, and what will work to enable the individual in coping with the experience, as evidenced by the narratives of this study. The issue here is that the diagnosis of fibromyalgia only explains part of the picture, and some of the symptoms in many of the cases. As previously discussed, there are multiple aspects that drive fibromyalgia, including psychosocial, physiological, behavioural, emotional, environmental factors (Arnold et al, 2008; Rosenzweig and Thomas, 2009). The diagnosis is simultaneously broad and exclusive, and thus can only address a collection and particular configuration of a host of symptoms that appear unpredictably and in diverse manifestations.

Furthermore, there are elements of fibromyalgia that are simply medically inexplicable. This does not make the entire condition derisive. Rather it is complex and largely difficult to diagnose and requires a genuine commitment to finding out the true cause of pain and exhaustion after having extensively eliminated any better explanations (Barker, 2011). As Råheim and Håland (2006) stated, pain is poorly understood and fibromyalgia as a contested condition only adds to the confusion and uncertainty surrounding both the nature, symptoms, trajectory, treatment options and legitimacy encountered by those living with it. Diagnosis as a process is meant to clarify, illuminate and explain. In the case of fibromyalgia as a chronic pain condition however, the inherently discrediting elements of the label, such as unpredictable prognosis, could actually serve to create less clarity, greater uncertainty and lead those living with the condition further away from understanding and explanation (Jutel and Nettleton, 2011; Råheim and Håland, 2006; Cunningham and Jillings, 2006; May, 2005).

Prognosis and Sickness

An explanation of illness behaviour as provided by Blaxter (2004) is useful as a typology for analysing the process of coping with fibromyalgia. It is also helpful in understanding the chaos and questioning involved, and the multitude of obstacles found on the path to wellness, particularly for those living with the condition. This process encompasses recognition of

symptoms and the perceived seriousness thereof. The typology also considers the point at which daily social activity is disrupted by these symptoms and the frequency and persistence of the illness. There are various psychosocial stages of illness behaviour included, such as family tolerance, denial or fear and the amount of access to knowledge and information available. The typology is completed by competing and conflicting interpretations of the symptoms; the treatment options obtainable by the individual; as well as the affordability and access to them (Blaxter, 2004). In being broad-reaching, this view of the process allows for accounts of disruption where illnesses do not conform to expectations, in their appearance, aetiologies, patterns, outcomes and treatment responses, as is the case with fibromyalgia.

The combined Bio-Psycho-Social-Environmental (BPSE) Approach is epitomised here in that symptomatic indicators are the key identifiers that lead to an individual being categorised as 'sick' (Gilbert et al, 2010). This is an important distinction for addressing fibromyalgia in that seeking uniformly applicable mechanisms to identify the condition will often fail to capture the heterogeneity and complexity of the condition. The BPSE also allows for the responses and reactions to that initial process to be heavily social in nature. This is because indicators such as sick-care availability and the ways in which social life is disrupted by the presentation of symptoms are used to account for illness (Blaxter, 2004).

'Illness', as mentioned constitutes the subjective and individual experience of lost health – thus it has a psychological component while ‘disease’ is an ‘objective’ biomedical label and category used to give a condition legitimacy and recognition following an encounter with a 'socially' recognised medical practitioner (Gilbert et al, 2010). This experience was described in detail in the previous chapter where subjective recognition of symptoms was transformed in meaning and status into the disease category of fibromyalgia as a diagnosis. The insecurity of the label of fibromyalgia has consequences for the patient experiencing the condition and the meanings of their symptoms. Furthermore, there are impacts felt in the interactions they are able to continue having around their illness with practitioners and social support networks.

While complexity was found in many aspects of fibromyalgia, it was particularly present in relation to securing **prognosis.** This affected the capacity of the individual to continually articulate their experience as legitimate and real. It also reduced their ability to present themselves as in need of care and attention from medical practitioners, their families, workplaces, social institutions and society at large. To reiterate, **'sickness'** is a social concept that refers to the societal component of the experience determined by the 'legitimate label' of the bio-medical practitioner (Gilbert et al, 2010; Van Hal et al, 2013). Help-seeking behaviour is characterised by a number of processes that move illness from a subjective, internal process to the objective, external component of sickness. Along the way, symptoms are reviewed and given new meaning. This occurs first through the recognition that they are no longer controllable or normal, then through the telling of the experience to different actors that direct action and leads to diagnosis, treatment and hopefully recovery (Lupton, 2003).

Blaxter (2010: 79-80) usefully explains that the 'sick role' in essence is "a contract of rights, obligations and privileges between the ill person, their doctors and society". For Blaxter (2010), gaining entry into the 'sick role' involves the recognition of the legitimacy of the illness. It further requires conformity on the part of the ill person to the norms and behaviours associated with the role. Blaxter (2010) particularly highlights the individual's desire to return to wellness and consultation and cooperation with health professionals as necessary in the interaction. In return, the ill person would receive the privileges of being excused from normal daily social life and responsibilities. They would also be seen as in need of care, support and understanding while not being held responsible for their condition. Fibromyalgia complicates this view of illness, primarily because it is chronic in nature. Additionally its aetiology is largely unknown and vague and there are multiple manifestations of the condition with several treatment routes that are not guaranteed to work. This was clear in the narratives of my participants as they attempted to legitimate their experience, and avoid being stigmatized and blamed for their failure to recover as expected.

The diversity of the symptoms associated with the condition, as well as the numerous actors, institutions and medical systems required to address fibromyalgia, ensure that regulating responses proves to be a challenging task. The Parsonian perspective of the 'sick role' is rigid and narrow in its formation and coverage, and is most applicable to acute rather chronic

illness. It still holds relevance to the analysis and arguments made here about how people with the condition seek answers and identify the parameters of fibromyalgia. This is because components of the conventional, Parsonian 'sick role' are prominent in shaping the illness perceptions, expectations and experiences of those living with fibromyalgia (Glenton, 2003).

This is enacted through the process of diagnosis and the requirement of interaction with healthcare practitioners in order to attain the status and identity attached to the 'sick role'. Van Hal et al (2013: 10), citing Williams (2005), critique Parsonian interpretations of the 'sick role' for not presenting "suitable norms for people living with chronic illnesses". The normalisation of symptoms in chronic illness experiences ensures that the meaning changes. Pain and exhaustion might have otherwise been viewed as transient, resolvable symptoms but when chronicity is realised, the response to the symptoms and the prognosis of the condition shifts (Richardson et al, 2006b). The narrow parameters of the Parsonian 'sick role' do not account for this change and as such, becomes less relevant in the case of chronic conditions. This study takes a similar approach to Edwards and Gabbay (2007: 164), as there was an attempt to explore how people experience sickness "in the context of their efforts to maintain a coherent identity in the midst of change".

It is this change that is vital in the critiques of Parsonian notions of the 'sick role'. This is because the characteristic features of *multiplicity, flexibility and unpredictably* found in fibromyalgia experience fail to slot into the rigid confines of that concept. Glenton (2003: 2244), citing Dumit (1998), explains that "individuals who experience bodily suffering but who fail to gain acceptance for this suffering find themselves with illness but without sickness and can be described as inhabiting a liminal space". This is certainly the case for fibromyalgia where the meanings, expectations and outcomes of the diagnosis's status in society continually recreate the patient's ability to occupy a legitimate 'sick role'. For this reason, it was necessary to investigate how this process unfolds, and the manner in which people living with a chronic condition marred by contestation (like fibromyalgia) effect help-seeking behaviour, when the traditional routes of care and support were obstructed.

Having said this, Parson's understanding of the 'sick role' is still important as it is centrally included in the perceptions, expectations and recommendations for recognising and responding to illness in many modern westernised societies, which SA has many features of (Lupton, 2003). Many of the experiences related by the participants of this study reflected elements of compliance to the traditional 'sick role'. However, complication and challenges were found in the shortfall between the variability of their symptoms and the expectation of the meanings of their condition in broader society. A critique of the Parsonian 'sick role', its limitations and continued dominance in institutional responses to illness are used in this thesis to illuminate and analyse the complexity of fibromyalgia as an illness experience in SA.

The organising mechanisms and potency of diagnosis was discussed in the previous chapter. In this section, it will be shown how the lack of explanation, expectation and response denoted by the diagnosis of fibromyalgia impinges on the credibility of the condition. It will also be shown how this in turn extends a period of "chaos" for the person living with the illness. It is also important to note the different ways that the reinforcement of these processes occurs. It is bolstered through the allocation of sick leave in workplaces, legitimation for the diagnosis in society broadly, as well as in the empathy and care given from those surrounding the person as they move through their illness (Hansson et al, 2006: van Hal et al, 2013). There is much complexity associated with fibromyalgia. In capturing the scope and outcomes of the condition through the narratives of those living with fibromyalgia, the chinks in the uniformed response to sickness, by patients, practitioners, institutions and society were displayed and analysed through this study.

As noted earlier, White (2002) explains Foucault’s view that medical practitioners enable a structure of power by labelling, categorising and prescribing those that are healthy and those that are not. Conditions like fibromyalgia, which have uncertain aetiologies, invisible markers of illness and broad diagnostic categories that overlap and meld with other conditions, are frequently relegated and ignored by biomedicine and its practitioners. Attaining diagnosis is challenging and, as argued later in this chapter, does not sufficiently ensure expectation of recovery. This in turn places those with contested conditions in a precarious position of being neither sick nor well enough (Nettleton et al, 2004). The questions of consistency are

particularly important in explaining why fibromyalgia as an illness presents so many challenges to conventional understandings of symptoms, diagnoses, prognoses and treatments. This is because fibromyalgia is the antithesis of homogeneity in its form, pattern, duration, outcome, treatment and social and institutional expectation. It also requires enormous flexibility in responding to the demands of the condition.

Having received the diagnosis of fibromyalgia, people living with the condition are thrust into a space of liminality where for the most part they are neither well nor ill (Mendelson, 2009). The biomedical approach is unable to effectively address these conditions in prescribing treatment and moving the patient out of their 'sick – role' and setting them on the course to the restoration of their health. Many of the participants in this study spoke about moving from doctor to doctor, seeking relief for their symptoms after the label had been dispensed. For explanation, they often turned to media sources in the form of books, journal articles and the internet, seeking reassurance, understanding and information (Lupton, 2013; Nettleton, 2004; Powell et al, 2003; Conrad and Stults, 2010). In determining that their condition was incompletely understood by biomedicine, they underwent a process of becoming experts (Barker, 2008). They attempted to know themselves and their condition in its entirety in order to see patterns and try recommended routes of alleviating symptoms.

These conditions have no organic basis and are essentially "non-diseases" (Smith, 2002). Dumit (2006: 578) furthers this definition by characterising these conditions as "incompletely biomedicalized" in that insufficient medical certainty surrounds the illness. The partial biomedicalisation therefore compromises the individual's ability to access, enter, and move through the 'sick role', as well as receive the medical and social care, support and legitimacy they need to return to a better state of health. Knowing what to do, who to consult with and what symptoms required care and attention were all concerns for the participants in my study.

Appearing to be a "good patient" and one who would not waste their medical practitioner's time was another feature of the narratives of my participants. In the context where there is a proliferation of and access to internet-based information, the participants became "expert patients". They often knew more clearly what their state of health was than what their body

might be showing at the point of consultation (Stockl, 2007). Before being able to restore health, participants spoke about being stuck in a period of chaos. At that point symptoms were overwhelming, knowledge evaded them, and legitimacy for their condition at many levels of their interactions (practitioners, social institutions and support networks) was scarce. Additionally treatment options that were offered were ineffective and, at times, worsened their condition.

Fibromyalgia is disruptive to the order and organisation that is central to the process of diagnosis. The condition presents many challenges to biomedicine as it is very difficult to pinpoint through medical tests, explain using conventional means of medical knowledge and treat with regimented medical therapies (Arnold et al, 2008). Fibromyalgia has an unpredictable and broad prognosis, which for the most part is positive and recovery is largely possible. However, as shown through this study, adaptability is critical, and the patient needs to be accommodated individually. In trying to systematise and prescribe generic sets of treatment recommendations, much of the nuance and complexity of conditions like fibromyalgia is lost and not addressed by biomedicine. This in turn relegates those with the condition outside the scope of medical practitioners and places responsibility for treatment and care increasingly in the hands of the patient (Stockl, 2007).

For Lupton (1997), the more applicable components of Foucault's theories that have been applied in medical sociology are those concerning the productive capacity of power. Specifically, Lupton (1997) asserts that Foucault's assessment of medicine's productive abilities shows it is an institution and structure in society that enables individuals to situate and understand themselves and their bodies in their context. This is the case with fibromyalgia. As patients, they have come to a label and description of their experience that confers with a body of recognised medical knowledge. They are enabled to discover and understand the meaning of their symptoms and develop ways of managing the condition.

There are levels of power being exercised continually in the duration of an illness career, many of which are reflected in the narratives collected from the participants of my study. Control, in a time of the chaotic illness experience of fibromyalgia, appears frequently as a

theme in the narratives of those I spoke to. There is a desire to regain one's sense of self and to overcome symptoms. They want to move through the experience in a forward trajectory and to receive care and understanding from their healthcare practitioners, medical insurance schemes, workplaces, educational institutions, families and social circles (Travers and Lawler, 2008; Wisdom et al, 2008). Following a Foucauldian approach, Lupton (1997: 99) states that, "power as it operates in the medical encounter is a disciplinary power that provides guidelines about how patients should understand, regulate and experience their bodies". This is evident as a practice in diagnosing, offering prognostic expectations and medical treatments in the course of addressing fibromyalgia.

The boundaries between wellness, illness and sickness blur within the experience of fibromyalgia as the symptoms feature sporadically or enduringly in the midst of other conditions. This creates a chaotic and unpredictable illness experience for those that live with it. Christakis (1997: 301) succinctly explains that the centrality of diagnosis in a clinical encounter is due in part to "prognosis and therapy [being] seen to follow necessarily and directly from it… Once a diagnosis is made and effective therapy is initiated, the clinical course of a disease is often presumed to be relatively fixed, non-individualistic, and standardized". This view holds relevance for acute conditions that have identifiable aetiology and effect treatment responses. This view of diagnosis and the interaction with prognosis and treatment also sits in direct contestation with the approach and outcomes found in attempting to address a complex and variable condition like fibromyalgia.

Christakis (1997) does acknowledge this and states that where there are limited options for therapeutic intervention or diagnosis or both, then prognosis should shift to being the central focus of a clinical encounter. This is a useful way to view fibromyalgia, in that the causes (diagnosis) and outcomes (treatment) of the condition are relatively difficult to capture. What is more easily viewed is the experience and broad pattern of the symptoms and illness. In capturing the general trajectory (prognosis) of when symptoms originated from and what attempts can be made to reduce severity and manage them, coping mechanisms can be developed. The narratives of this study showed the urgent need to shift the focus from explaining causes and finding meanings towards accepting, accommodating and adapting to the condition.

In this view, prognosis is not uniform, the endeavour is not to standardise response, and flexibility is the approach. Displaying this trend and the effectiveness of changing the focus from diagnosis as the site of contestation to prognosis were two critical outcomes of this research process. The findings that emerged in the course of this study contribute to an understanding of fibromyalgia that is holistic, and places the patient as a priority in informing the expectations, responses and requirements of living with the condition. This perspective develops Christakis (1997: 302) assertion that "clinical thought has progressively moved from an individual-based to a diagnosis-based conceptualization of disease, that prognosis has been progressively presumed to be intrinsic to diagnosis and therapy, and that explicit attention to prognosis has consequently diminished".

The ‘sick role’ is a particularly important concept for this study because within the influence and scope of it, people living with fibromyalgia are able to negotiate legitimacy for their experiences and draw on medical and social support for their condition. The interaction of ‘illness’, ‘disease’ and ‘sickness’ was important to capture. This was because the boundaries between the individual, subjective experience; biomedical, objective categorising; and societal expectation and recognition blur in cases of medically ill-defined conditions (Dubin, cited in Ride, 2010). For Gilbert et al (2010) embodying the 'sick role' involves meeting societal expectations, norms and values around health and illness in terms of behaviour and visible signs of disease. Where these expectations cannot be adequately met, the individual experiencing illness faces continual challenge in describing the nature of their condition. This involves responding to questions of why they do not look ill and why they are unable to perform normally in a range of social roles due to their illness. Living with a condition that did not conform to societal expectations of illness resulted in feelings of failure for those experiencing illness. This was because they precariously occupied the 'sick role', and could be cast out momentarily and by multiple actors.

Sickness and the Illness Career

The process of moving from a healthy person to a sick patient is facilitated and negotiated by the individual's socially and culturally learnt responses. These can both assist and hamper efforts to restore wellness (Blaxter, 2004). Critical to the process of moving from health to sickness is the availability of and access to medical practitioners, facilities, treatments and knowledge that are supportive of the patient in their illness experience. Perceptions of health held by the individual and the meanings thereof shape the consequent action of recognising symptoms and seeking help. Acknowledging disruption and the signs of disease as well as the mechanisms utilised in returning to health is a process shaped by many factors. As discussed earlier, the social, cultural and structural characteristics of the knowledge sources around health and illness, as well as sick-care, affect how the individual approaches their illness experience. It also subsequently affects how the individual reacts to that experience in terms of help-seeking behaviour and their responses to treatment. With fibromyalgia, as with other chronic illnesses, there are elements that distort the trajectory of these processes. These include the contestation over the legitimacy of the condition, normalised sickness and lack of appropriate responses, in terms of medical knowledge and treatments (Sim & Madden, 2006).

Part of developing a visible prognosis for people living with chronic illnesses such as fibromyalgia is accounting for the multi-faceted, complex nature of the condition, where movement between health and illness is frequent and unpredictable. It is important to acknowledge that there are disabling elements, both physically and socially, that are patterned, if not always visible. This is additionally useful in capturing the layered and challenging illness experience of fibromyalgia. As Raff et al (2014: 79) note, "chronic pain patients are more likely to report anxiety or depression and significant activity limitations and often have unfavourable perceptions of their health". Much of the challenge of living with fibromyalgia relates to the attempts of being a legitimate patient; presenting oneself in medical encounters and in society as sufficiently unwell to need care, support and treatment (Werner & Malterud, 2003).

Attempting to enact uniform and rigid recommendations and responses to fibromyalgia as a condition and those living with it is a fruitless enterprise, which results in frustration for the

patient and those who care for them. Biomedicine frequently fails to explain fibromyalgia as a condition beyond dispensing a label and an account of expectations and treatments that vaguely and generally deal with the illness experience. Because fibromyalgia is not easily understood in the biomedical framework of diagnosis, prognosis and treatment, much contestation persists around the status of the label and the routes and recommendations that can be taken in capturing and treating the symptoms associated with the condition. The condition and those living with it are marginalised in the medical discourse of health and illness, partly because it is not easily recognised, categorised or explained by biomedicine, as discussed earlier.

In this regard, Nettleton's (2006a) discussion of biomedicine's ambivalent stance towards cases of illness that do not present a specific aetiology is compelling. She goes on to show that for those with unidentifiable illnesses, life becomes a state of uncertainty that cannot be reduced nor removed. The continuous challenge of overcoming uncertainty is present in the narratives of the participants explored in this thesis. Knowing what symptoms were related to which condition and what expectations could be held about health and illness experience were frequent concerns for these participants. In navigating through their illness experiences, finding relief from their symptoms was a large part of their attempts to manage their fibromyalgia, and the hurdles related to what could be known with certainty were acutely felt Undeland and Malterud, 2007; Åsbring and Närvänen, 2004). The lack of certainty surrounding fibromyalgia casts the individual living with the condition into a questionable position, as both a patient and a person, where their credibility is scrutinised. The invisibility and multiplicity of many of the condition's symptoms undermines the ability of the person, and those surrounding and caring for them, to explain what is happening. This in turn presents challenges in knowing the severity of the experience and, most importantly, how to respond to what is happening to the person.

Both Stockl (2007) and Cooper (2002) use the notion of an "illness career" to explain people's illness experiences and the resultant conflicts and contradictions that occur in the face of medically ill-defined conditions. Cooper (2002: 181-182) defines an illness career as "a progression of an individual through a series of positions in an institution or social system each having implications for the social status of the person concerned". Stockl (2007: 1550)

expands on this sentiment by locating the phenomenon in late modernity, in relation to medicine's tendency to create a "body multiple". For Stockl (2007: 1550) this process "has an effect on the way we conceptualise the relationship between mind and body, self and society disorder and order". In doing so, we simultaneously search for clarity, and this gives rise to "multiple meanings for a singular phenomenon" (Stockl, 2007: 1550). This relates to the study of fibromyalgia experience undertaken here, as the processes and meanings that develop in addressing the complexity of the condition was explored through this research.

Nettleton (2006a) refers to the fact that biomedical approaches to health and sick-care employ aetiological and physiological explanations and mechanisms that are essentially asocial and amoral. This means that there is an attempt being made to understand a personal, culturally and socially shaped experience like fibromyalgia through the utilisation of diagnostic procedures that are biological, clinical, microscopic and exclusionary. By drawing on this process, it appears that the social and moral ways in which people make sense of their social world, and enact particular roles in relation to health and illness, are contradicted. Dumit (2006: 577) further explains the impact of relying on biomedical diagnoses for illness experience and the attached difficulties found "in the case of emerging uncertain illnesses… [As] the resulting judgement may be that despite symptoms, there is no care that can be offered. This judgement in turn impugns the person's legitimacy to make a claim and to be suffering, denying them the sick role altogether".

This is not precisely the case for those living with fibromyalgia, as some care is offered and partial entry into the 'sick role' is allowed. However, in the experiences of those who have contested conditions, like fibromyalgia, where certainty, clarity and prediction are all elusive, the process does not move in a uniform trajectory from diagnosis to recovery. Dumit's (2006) research on experiences of CFS and MCS show the critical role that "facts" and information play in the negotiations and relations surrounding illness, diagnosis and treatment. Dumit (2006) states that people with conditions that are medically ill-defined constantly encounter a system in which they must provide facts and physical, biological evidence of their suffering in order to legitimize their experience. While people with fibromyalgia are mostly able to access a diagnosis and vague explanation, they are not afforded a concrete prognosis or

symptom relieving treatments. Showing these nuances in the effects of delegitimation for people with fibromyalgia was a key contribution of the study detailed in this thesis.

The certainty gained through a diagnostic label is then diminished as the experience becomes fraught with complexity. This is because guiding routes and remedies are not instantly available to the practitioner or their patient. Overcoming fibromyalgia involves accepting the experience in a holistic manner that does not question too deeply the invisibility of the condition. Rather, the approach should encourage the person living with the condition to empower themselves, through knowledge of their symptoms, and treatments that work for them (Oliver et al, 2001; Hassett and Gevirtz, 2009). Despite the recognition of the importance of this approach for assimilating and normalising fibromyalgia into one's health and illness experience, scepticism is still rife about the meanings attached to the condition.

Certainty is desirable and crucial because it holds authority, and the more objectively recognised a phenomenon is, the easier it becomes to deal with it. Dumit (2006: 578) explains that facts are subject to manipulation by individuals, "physicians, families, researchers, corporations, insurance and administrative agencies" (Dumit, 2006: 578). They are malleable because they are meant to bring clarity and resolve to medical matters, and determine who is sick and how they are meant to be ill. The reliance on "facts" to guide our understandings of health and legitimate illness, and the ease with which they serve the wills and purposes of various actors has proven to be testing for those living with fibromyalgia. In experiencing a condition that can be debilitating at times, the proving of facts through biomedical indicators, consultations, seeking knowledge online and finding treatments that work forms an additional layer of complexity to an already confronting condition.

Jackson (2005) usefully discusses the complexity of chronic pain and its conversion into illness, and the barriers to inhabiting the 'sick role' that emerge in this process. While pain is a common medical symptom, the severity and intensity of the pain being felt is difficult to measure and there are many confounding factors that can mask its presence and meanings. As Jackson (2005: 333) noted,

> Another complication is that the distinctions between the experience of pain, pain behavior (any behavior seen to result from a pain experience), and certain emotional states seen to often accompany, rather than constitute, pain (such as suffering, depression, or demoralization) can be, and often are, highly ambiguous. Chronic pain's chronicity- that it never ends- means that it is accorded less legitimacy than acute conditions.

People with fibromyalgia, or with other pain and chronic conditions, are often placed in a liminal, ambiguous state of being neither well enough to be normal, or sick enough to be afforded the status and legitimacy of the 'sick role'. Jackson (2005) explained that when people and their symptoms cannot be categorised, they could experience rejection. They are also seen as "polluted" which explains some of the stigmatisation and disregard frequently experienced by people with chronic, contested conditions such as fibromyalgia. People living with the condition cannot be easily understood and interpreted through recognised frameworks of medical diagnosis, prognosis and treatment. Due to this, there is a figurative and literal "turn" away from them, which predominantly takes the form of inadequate treatment from health practitioners (Cohen et al, 2011). In society, people with chronic conditions like fibromyalgia also face a state of liminality, as their illness does not allow them accommodation in their workplaces, families, social interactions and individual roles and identities. Their experiences and responses to their condition from practitioners, institutions, families and friends stand in contrast to others who are seen to have "legitimate" illnesses, and this was discussed in the narratives of the participants of this study.

Sim and Madden (2008) report that fibromyalgia patients favoured biomedical explanations of their symptoms and experience, while rejecting and resenting psychological labels for their disease. Having been diagnosed by a biomedical practitioner, Sim and Madden (2008: 62) relate that the patient experiences relief and validation that their illness is real and they as a patient are credible, as well as the reassurance that the condition was not life-threatening, all of which brought “meaning and clarity to an ambiguous situation”. This process was reflected in the narratives of my participants. Importantly, however, Sim and Madden (2008) point out that inadequate prognosis pushed the patient back into the same distress and confusion felt in the pre-diagnosis stage.

Despite the initial excitement and validation found in receiving a concrete diagnosis, the uncertainty and lack of improvement experienced following the identification of the disease meant their status as a patient and the label of fibromyalgia eventually lost credibility (Undeland and Malterud, 2007). This was evident in the narratives collected for this study and displaying this shift from diagnosis to prognosis as the site of contestation was an important contribution of this research. The loss of initial credibility was shown through people with fibromyalgia continually seeking better and clearer explanations for their condition, primarily from sources of biomedical knowledge. Having gained a label, but not a concrete prognosis, for determining how to live with their condition, many participants engaged in chaos narratives as they jittered between practitioners, sources of information and treatment options, seeking relief and explanation (Frank, 1997).

While fibromyalgia suffers were able to access "a number of traditional and complementary treatments" following diagnosis, they "struggled to achieve understanding and relief from such treatments" (Sim and Madden, 2008: 62). The subsequent sense of illegitimacy felt by people living with fibromyalgia was explained through the perception that inadequate knowledge existed around the condition. This created deficits in interest, support and care from health care professionals, or family and friends, or both. The lack of cure for fibromyalgia further alienated patients from their caregivers who appeared unbelieving and uninterested in their experience. This also draws on the fact that biomedical knowledge and practice is valued much more highly than patient experience. Thus, a tension emerges when clinical, objective explanations are unable to account for subjective, 'invisible' felt experiences (Sim and Madden, 2008).

Fibromyalgia emulates the notion of 'deviant' illness as it cannot be readily understood, medically and socially, and those living with it are then often cast negatively in the expectation of overcoming illness. While this is also the case for many chronic illnesses as they are incurable, it is aggravated in the case of fibromyalgia, due to the lack of credibility surrounding the condition emanating from the uncertain aetiology and treatment options (Barker, 2011). As Lupton (2003) explains, traditional understandings of the 'sick role' are not adapted easily to chronic illness and are unevenly applied to those living with chronic conditions. People living with chronic conditions must "adapt to their role, 'manage' their

illness and accept impaired functioning as a normal state rather than a 'deviant' state" (Lupton, 2003: 98). The process of normalising illness cements the liminality of living with chronic conditions in that what was deviant becomes expected, and responses then change (Jackson, 2005).

While much of chronic illness research focuses on issues surrounding medical and social credibility and diagnosis, the data explored and analysed in this thesis shows the continuation of this process and its associated problems after the diagnosing encounter. There is ambiguity in the position occupied by the sick person. They know they have a condition, but it does not always affect to a debilitating degree their functioning as expected from the model 'sick' person. Furthermore, they cannot predict when symptoms will manifest, or what triggers might cause symptoms to appear. Citing Turner (1969/1997), Mendelson (2009) characterises **liminality** as necessarily ambiguous, as people and their conditions evade the categorising framework that gives entry to particular statuses in society.

Diagnosis as a site of explanation is also supposed to provide guidance of response to illness. Where discrepancies appear because associated treatments are not assistive or components of the condition remain unknown despite being named, diagnosis only partially allows for legitimacy and credibility of the patient in their occupation of a sanctioned 'sick role'. In the case of fibromyalgia, a legitimate and defined 'sick role' is not proffered to those living with the condition. This is because the condition is elusive and ungraspable in medical terms - it is difficult to diagnose and the knowledge that surrounds the condition is highly contested. In discussing lupus illness experience and MUS generally, Mendelson (2009) explores the way in which chronic illness defies the usual routes that wellness and sickness is expected to follow. The liminality of contested chronic conditions means that people with the condition are placed in an ambiguous position of knowing they are unwell and are often diagnosed as such.

However, following that encounter, they have no recourse for furthering their task of restoring health to themselves because the practitioners and systems traditionally assigned to

assist in these matters simply cannot do so effectively. Mendelson (2009: 403-404) explains that

> for people [with lupus] experiencing troubling, painful, and often disabling symptoms, this diagnosis can be very disturbing because it offers very little hope for effective treatment… [In addition, they] are denied the "sense of legitimacy" that comes with a named diagnosis. In addition, their search for information and sources of social support are hampered because they do not know to which group they belong, and their attempts to access benefits of a sick role are not seen as justified.

Knowing they have a condition and having a name and a basic explanation for it does not ensure that they will be able to fully embody their illness, in a societal sense, as they continually face de-legitimisation, scepticism and disregard from the systems, practitioners and people that are tasked with supporting and caring for them. Exploring the ways these processes play out in the illness experience of fibromyalgia was a central task of the research undertaken here.

Treatment

Normality and treatment trajectories in chronic illness

While attempting to make sense of a medically ill-defined condition and the associated illness experience, people seek ways of understanding their state of health. They often do this through alternative mediums, which correspond to their cultural, spiritual and social belief systems, and arise from sources that are easily accessed and in their immediate environment (Aggleton, 1990). This process is evident in the case of people diagnosed with fibromyalgia and other medically ill-defined conditions, as there is a degree of credible biomedical explanation for their experience. However, the explanation offered is shrouded in vagueness and uncertainty and subsequently can produce more difficulty and challenge for the patient as they attempt to shift themselves through and out of the 'sick role' (Sim & Madden, 2008). In sensing failure on the part of the biomedical sciences to explain and treat their condition, people with fibromyalgia also consult with alternative practitioners and different sources of health knowledge.

This is done in determining how to negotiate their illness experience and how they can best manage their condition. An emphasis is placed on the need to employ new and innovative conceptual tools that explain the complexities of the interaction between identity, culture and medicine (Broom et al, 2009). This is achieved through understanding how people interpret their perceptions and beliefs of health and illness, as well as how they enact the social roles of 'person' and 'patient'. McQuaide (2005) argues that the social conditions seen in the post-modern era create a ripe environment for CAM to blossom and embed itself within societies alongside orthodox, conventional biomedical healing systems. This further highlights the social nature of people's understandings of and interactions with health and illness as the social structures and conditions establish particular forms and knowledges of healthcare within a society.

The contested status of fibromyalgia as a disease and the lack of available and effective biomedical treatment for the condition (or clear prognoses) provide a perfect lens through which the issues raised by McQuaide (2005) can be investigated and analysed. People living with fibromyalgia fall into these gaps between conventional, allopathic biomedicine, and alternative and complementary medicine. This allows for insight to be gained about the motivations and processes that drive patients to continually seek out a better state of health or explanation for their experiences and condition. McQuaide (2005: 288) takes a simple approach in defining CAM, as for him it is "anything done or given to the patient that is outside the limits of orthodox medicine". When the chronicity of a condition has been realised and hope for cure has diminished, the expectations of **'normality'** change (Sanderson et al, 2011). As explained above, the trajectories of fibromyalgia ensure that uncertainty, unpredictability and flexibility are features of the experience of the condition.

Part of the challenge of living with chronic illness is the fact that the illness is continually disruptive and, rather than entering one's life as a unitary event, there is the requirement of complete adaptation to cope with the condition (Richardson et al, 2006a). People with fibromyalgia move away from restitution narratives as they realise the chronicity of their symptoms. As they do so, it is also clear that they enter into chaos narratives as they attempt to find the parameters of their condition (Whitehead, 2006; Nettleton et al, 2004). In the period when treatment is successful and symptoms abate and become manageable, it was shown through this study that participants were drawing on quest narratives to explain their

experiences. They discovered new forms of normality, which correlated with the ability to cope with fibromyalgia. Thus, people involved in this study were able to experience their "illness as a metaphorical journey from which the ill person may gain self-awareness, or the ability to help others" (Nettleton et al, 2004: 50).

Sanderson et al (2011) in discussing rheumatoid arthritis, show the complexity of defining and creating typologies of normality. These complicating factors include the predictability and visibility of the symptoms, whether prognosis can be given and whether or not stigma affects the experience of the condition (Sanderson et al, 2011). The types of normality outlined in their discussion include: "disrupted normality", "resetting normality", "struggling to maintain normality", "return to normality", "fluctuating normality" and "continuing normality" (Sanderson et al, 2011: 629-630). Like with rheumatoid arthritis, fibromyalgia creates complexity where biographical disruption is not necessarily a uniform experience. Furthermore, with the fluctuations and movements between relative wellness and severe, deep illness, categorising experience within a type of "normality" can be challenging with little connection between the two notions. For the purposes of the descriptions detailed below in the findings of this study, Sanderson et al's (2011) explanation of "shifting normalities" has been adopted in the similar overarching fashion as was used in their study.

Sanderson et al (2011: 618) utilise the concept of "'shifting normalities' [which provides] a dynamic explanatory model of chronic illness that captures the interaction of changing conceptions of a normal life and the normalisation of symptoms". In attempting to understand a condition like fibromyalgia, the explanation of 'shifting normalities' is useful as it illuminates many of the complexities inherent in the multiplicity and interconnectedness found in the experience of the condition. Fibromyalgia as an "event" is not singular. Rather it is a continuous process of adaptation and normalisation where attempts to pinpoint the parameters of the condition and respond to the symptoms are made frequently in order to reduce the severity of the symptoms and manage the condition (Travers and Lawler, 2008).

Schachna and Littlejohn (1999: 477) explain that "critical to good outcome is the need for an understandable explanation of the mechanism of fibromyalgia and introduction to self-

management skills that include exercise and techniques that minimize aberrant responses to psychosocial stressors". The ways that people living with fibromyalgia are enabled in developing skills and strategies in coping with the condition was a central objective of the study undertaken here.

Approaches and types of treatment for fibromyalgia

Watson (2003: 129) explains that "chronic pain is a condition of such complexity that it can only be addressed by multidimensional assessment and treatment". Arnold (2010: 396-397) notes that,

> Because the clinical presentation of FM is heterogeneous, treatment recommendations must be individualized for each patient… Recent evidence suggests that comorbidity and the presence and severity of symptom domains are important when selecting initial medication treatments for FM. Pharmacological treatment may help patients experience enough relief of symptoms to begin an adjunctive exercise program. Patients should be instructed to begin a program slowly and to pace themselves based on their level of fitness. Integration of psychoeducational approaches, including education about the disorder, support groups, and CBT[4], may also be helpful in improving patients' ability to cope with FM.

Here, the multiplicity of fibromyalgia is displayed as treatments prescribed aim to address the diverse symptoms of the condition in tandem (Lewis and Johnson, 2006; Daya, 2007; Aalbers, 2012). Treatment for fibromyalgia is complex and accordingly, practitioners and patients have to be responsive to the condition, the needs of the patient, and the limitations imposed through the experience of the illness. Raff et al (2014: 81) explain that, "complete relief of pain is rarely achieved in patients with CNCP[5] and the physician should ensure that the patient's expectations of therapy are realistic. The goals of management are to reduce pain intensity and to improve the patient's functional levels in relation to physical, vocational, social and emotional wellbeing". Mease and Choy (2009: 359) note that

> Historically, clinicians have empirically prescribed pharmacologic therapy for fibromyalgia (FM) based on patterns of specific symptom domains without the imprimatur of formal

[4] Cognitive Behavioural Therapy
[5] Chronic non-cancer pain

> approval by regulatory agencies or even a clear understanding of pathophysiology of the condition to guide treatment choice. For example, it has been common to treat musculoskeletal tenderness with medications such as nonsteroidal anti-inflammatory drugs (NSAIDs), muscle relaxants, and narcotic analgesics, sleep disturbance with sedative hypnotics, and disturbance with antidepressants.

In this picture, there is an additional component that plays a significant role in shaping the health outcomes of people with fibromyalgia, namely effective treatments. The use of some pharmacological treatments create iatrogenic effects. The treatments are also diminished in their efficacy over time (Mease et al, 2010). From the narratives collected in this study, it was evident that treatments that provided relief were hard to come by. Furthermore, there needed to be high levels of cooperation between the patient and practitioner in order to finding workable treatments that were cost-effective and reduced symptom severity successfully. Within fibromyalgia treatment there is also a heavy emphasis on educating the patient and enabling them to manage their condition through a combined approach of appropriate medication, mindfulness and exercise (Bülow and Hydén, 2003; Ang et al, 2011, Derman et al, 2011).

Thompson et al (2011: 41) explain that fibromyalgia is a "common but incompletely characterized syndrome of widespread pain, tenderness, and fatigue that has been associated with high healthcare utilization". Mody and Brooks (2012: 246) note that the strategies "for the prevention of MSK[6] disorders [such as fibromyalgia] include maintaining an ideal body weight, balanced diet with adequate calcium and vitamin D, regular exercise, avoidance of smoking and alcohol abuse and a safe and ergonomically suitable work environment". In this, Mody and Brooks (2012) are showing the need for overall good health in order to prevent or reduce the incidence and impact of conditions like fibromyalgia and rheumatoid arthritis. Thompson et al. (2011: 40), having researched a cohort of fibromyalgia patients involved in a long-term treatment programme, found that the direct cost of fibromyalgia treatment was about twice that of a matched control group. There are abnormally high costs related to diagnosing and treating fibromyalgia, which in part is due to the difficult of identifying the

[6] Musculoskeletal

condition. It is also to do with the myriad of combination options for care offered to improve and maintain the patient's state of health.

Treatment adherence

The impact of costly medications and treatments was shown through the narratives of the participants in my study. The inaccessibility of treatments was profoundly felt by those participants who then experienced worsening symptoms and were less able to cope. Maintaining one's health was a delicate balance between effective medications, stress reduction and accommodation from work and family in order for the individual with fibromyalgia to rest sufficiently (Werner and Malterud, 2005; Audulv et al, 2012; Butow and Sharpe, 2013). As Oliver et al (2001: 2712) show, education in group based therapy sessions "led to improvements in both pain and functional status for patients with FM, as well as providing them with new ways to cope, increasing understanding of the syndrome, and teaching them the importance of exercise". Arnold (2010) explains that while cardiovascular fitness training is beneficial for fibromyalgia patients, some have difficulty initiating a regime because of the pain and fatigue they experience. The fear of over-exertion and the challenge of exercising when one feels sore and tired were also barriers for the participants of the study undertaken here (Derman et al, 2011).

Thompson et al (2011: 41) note that "multidisciplinary treatment strategies, often with a cognitive-behavioural component, have been shown to result in improvement of symptoms and function in FM". The study presented by Thompson et al (2011) focussed on a programme that included an education intervention facilitated by a nurse as well as self-care strategies that had components of cognitive-behavioural principles, physical therapy and occupational therapy. Patients were encouraged to manage stress, rest, relax and plan for days that would inevitably be difficult as part of their treatment. Interestingly, while all of these treatments are medical in nature and fall within the allopathic, biomedical sphere of care, the use of prescriptive pain medication is absent in this programme. The drive towards self-care and the experimental attitude needed in order to find successful management strategies for

coping with fibromyalgia was evident in the narratives of the people interviewed for my study.

People in this study behaved similarly in the self-management of their condition to those involved in the research undertaken by Audulv et al (2012). Audulv et al (2012) elaborate that initially information about self-management of their condition is sought by the ill individual, and a variety of sources are drawn on in this process including family, friends, healthcare providers and the internet. This potentially moves patients away from the "pharmaceuticalized" understanding of their illness as discussed by Barker (2011). Seeking self-management was also premised on the perception of need, as the individual had to manage symptoms, come to terms with their condition and find new ways of coping with their altered life (Audulv et al, 2012). This process is reflected in the narratives of the participants of this study conducted in SA. Thus, uncovering the strategies found and the sources consulted was an important way of explaining what treatments and means of management are helpful in coping with fibromyalgia as a chronic condition.

As Nielson and Harth (2004: 631) note, similar to "other chronic pain conditions - from cancers to migraine to low back pain - FM is a complex, biopsychosocial disorder". The condition is an amalgamation of physical, emotional, environmental and behavioural factors that produce pain and exhaustion as an unmanageable and overwhelming experience and is received in society with scepticism and suspicion (Barker, 2008). In discussing health policy assumptions, Gately et al (2007: 934) assert the importance of "acknowledging the complex, contextual and recursive nature of health service utilisation operating in the life worlds of patients' experiences of living with a long-term condition". In viewing narratives of those living with the condition, the ways in which interactions with healthcare practitioners, efficacy of treatments and social acceptance and support all shape the experience and story told was important to explore.

The multiplicity of causal possibilities for fibromyalgia as well as innumerable responses to the condition make tackling and managing the condition a continually challenging task (Arnold, 2010). Adopting a reflexive, holistic and open approach to treatment of the

condition works infinitely more effectively than attempting to capture the experience as a singular phenomenon that can be addressed narrowly and uniformly (Raff et al, 2014). Furthermore, by emphasising the importance of self-care in fibromyalgia treatment allows for the understanding of ways in which the practice contributes to and shapes help seeking behaviour and beliefs. Self-care is broadly described by Gately et al (2007) as the actions taken by the individual in caring for their physical, emotional and psychological well-being and health, as well as management of long-term conditions and prevention of further illness. Alongside the use of treatments, education plays a critical role in shaping self-care practices and behaviours and is a core feature of the treatment protocol for fibromyalgia (Gately et al, 2007; Meyer, 2006).

In discussing treatment for CFS, Ax et al (2001: 168) note that the uncertainty surrounding the aetiology and

> its varying symptomatology [has] encouraged the development of numerous self-help coping strategies and treatments. These range from increased rest, vitamins and minerals, diets, complementary and alternative medicine (including socially accepted therapies such as acupuncture or homeopathy) […] and antidepressants, to counseling and psychotherapy, to name just a few. It is striking that a majority of sufferers cope by increasing rest and reducing activity levels.

For the people with fibromyalgia involved in my study, adaptability and reflexivity were central to the development of coping strategies. As Ax et al (2001) assert - rest and reduction of activity were important components of managing chronic conditions like fibromyalgia and CFS where exhaustion was a core symptom. Butow and Sharpe (2013: S102) explain that while,

> there are many practical reasons why optimal interventions for both acute and chronic pain are not always used, such as lack of availability or accessibility of treatments, 2 other factors contribute to underuse of effective treatments. First, in some instances, effective treatments are not prescribed due to inadequate health provider knowledge, assessment, or practice. Second, even when practitioners prescribe or recommend an evidence-based treatment, there is evidence that many patients are nonadherent to the recommended treatments.

The simultaneous use of various means of overcoming symptoms entails that a level of experimentation is needed in order to establish which treatments and strategies are assistive. Similar to the process of diagnosis, working alongside a practitioner who acknowledges the complexity of conditions like fibromyalgia and is willing to address the symptoms and patient in the manner and approach required is an important step in getting effective treatment (Butow and Sharpe, 2013). As Gately et al (2007) discuss, in long-term management of chronic conditions there are different points at which healthcare utilisation is higher or lower. In ensuring treatment is dispensed and used appropriately, recognition for the demands of the condition being addressed is necessary.

Adherence to treatment can be challenging for people managing myriad symptoms. This is because the symptoms are so variable and the efficacy of treatments is unpredictable. The perceptions a patient has of their condition impacts their experience of symptoms (Graham et al, 2008). Morris et al (2011: 2), citing Oliver & Cronan (2002), Sullivan et al (1995) and Edwards et al (2006), discuss the fact that,

> Poor compliance towards exercise and other treatments is a common trait among FMS patients and is the primary factor contributing to the chronicity and accelerated deterioration of the condition. A key predictor of poor compliance towards exercise or activity has recently been identified as pain catastrophizing; a cognitive strategy broadly defined as "an exaggerated negative orientation towards actual or anticipated pain experiences" which significantly contributes to the maintenance of chronic pain.

The findings of the research detailed herein explored treatments used, and the facilitators and barriers to adherence. This is discussed in a later chapter.

Institutional Interactions

Biomedicine maintains its dominance through its ability to explain, respond to, predict and treat disease, and prescribe medications and determine parameters of sickness. In doing so, it frequently rejects conditions that fail to be accounted for in any or all aspects of the diagnostic and treatment process. By asserting its authority and dispensing legitimacy for illness and sickness, biomedicine is a powerful recognising force for orientating the patient,

practitioner and society in understanding, interpreting and addressing various illnesses. Having said this, it is important to acknowledge the normative buy-in attached to this process. Lupton (2003: 120) explains this using the example of both the doctor and patient who "subscribe to the belief of the importance of medical testing, constant monitoring and invasive or embarrassing investigative procedures in the interests of the patient".

As previously discussed, fibromyalgia has an insecure position in terms of medical legitimacy as the causes of the condition have yet to be accounted for in biomedical discourse. Additionally the unpredictable prognosis associated with fibromyalgia further undermines the credibility of the condition. Many illnesses are incurable and still remain within the fold of biomedicine. However, conditions like fibromyalgia that are often untreatable and require individuality and ingenuity in developing responses to the symptoms find themselves pushed to the edge of biomedical scope. Furthermore, the people suffering with these conditions are subject to scepticism, outright rejection and feelings of failure when their experience cannot be accounted for and addressed in the setting they traditionally expect to receive support in, namely in biomedical practice (Jackson, 2005; Barker, 2008).

Sim and Madden (2008) demonstrate the hegemonic authority that biomedicine commands in health and illness discourse and the implications of this central role for people's social lives. In applying sociological theory and concepts to chronic illness (as called for in studying fibromyalgia and illness experience), they demonstrate that "perceived ill-health or disability in others may disrupt the assumptions of 'ordinariness' and 'normality' that underlie social interaction" (Sim and Madden, 2008: 58). This indicates the broader relationship of health and illness in composing social identities whereby 'healthy' and 'sick' are binaries that are attached to others such as 'normal' and 'abnormal'; 'accepted' and 'rejected'; and 'desired' and 'shameful' (Scrambler, 2009). Where conditions conflate this notion of sickness through their inexplicable aetiologies and unfamiliar responses, the trend is to reject both the condition and the person experiencing it, as they do not fit neatly into the expected routes and responses. In disregarding their experiences, the legitimacy of a 'sick role' diminishes making access to continued treatment and empathy challenging.

In identifying the self-reported needs of women with chronic pain, Skuladottir and Halldorsdottir (2011) noted that ranges of interactions were included in these needs, which drew on the involvement and support of a variety of actors. Skuladottir and Halldorsdottir (2011: 81) grouped the needs into clusters of needs or, as they termed,

> major quests: The *quest to learn to live with the pain*, which involves the need for diagnosis; the need to find effective treatment and keep the pain tolerable; the need for helpful advice and information and the need to take care of self and for a different pace and a new life pattern. *The quest for support, caring and connection* which involves the need for someone close who cares; the need to be connected to others and have someone to care for; the need for practical support e.g. financial support and household assistance and the need for professional support and caring. Finally, *the quest for normalcy* which involves the need to avoid the sick role and maintain a sense of dignity; the need to focus on personal strengths and prevent discouragement and depression; the need to be involved in decision-making regarding own care and treatment and the need to participate in family and social activities to fight isolation and loneliness.

These needs were also reflected in the narratives of the participants of my study. The levels of quests, from coping with pain to seeking support and care as well as the attempt to restructure a sense of normality, are useful categories, which will be used continually throughout the analysis discussed later in this thesis. Skuladottir and Halldorsdottir (2011) helpfully capture the complexity of chronic pain and show the various components that determine the outcomes of the experience, such as finding treatment that works and self-management of the condition. Supportive home and working environments and collaborative relationships with practitioners that enable active decision-making for the patient were also necessary in this process. These interactions and factors are explored in the literature found below and are a useful typology for explaining many of the experiences related by my participants.

Workplace interactions

In a discussion of workplace absenteeism and sickness attendance among people with neck or back pain Sweden, Hansson et al (2006) explain that different strategies and models can be used to describe their experiences. Importantly, Hansson et al (2006) note that pain can cause

absence from work due to sickness at different points in the patient's illness career, according to whether the pain is reoccurring or chronic. In a balance of risks, short- and long-term sickness and workplace absence was negotiated through a range of factors and resulted in forms of "'presenteeism'… or 'sickness attendance'" (Hansson et al, 2006: 2184). Citing Aronsson et al (2000) and Perkin et al (2000), Hansson et al (2006: 2184) explain that "sickness presenteeism [occurs] in organisations where the absent employee cannot be replaced, thus sick-leave causes negative consequences for the absentee, workmates or a third party".

In the case of chronic pain and unaccommodating work environments where recurrent or continuous sickness is not accounted for, people with conditions similar to fibromyalgia may have to go to work while still sick. This is complex because, within the experience of chronic conditions, the premise of sickness is ever-present and the factor that changes or is negotiated around is the extent to which the symptoms can be managed (van Hal et al, 2013). Where the experience of illness is overwhelming then strategies to accommodate the symptoms through applications of sick leave or deferral of examinations and other commitments are used. The fact that the person is continually ill, but able to tolerate their symptoms and function in the workplace relatively unabated means that where possible, sickness presenteeism will occur.

Unlike in Sweden and for the people involved in Hansson et al's (2006) study, there is less provision and capacity to claim sickness absence or disability benefits in the SA context. This means that in coping with a chronic condition, there is little support for people in SA to navigate through their illness experience without encountering barriers to claiming sickness within their workplaces (Rosen and Simon, 2003). As Hansson et al (2006) describe, after an initial or intense experience of pain, there will be urgency for the individual to report themselves as sick. However, for people involved in Hansson et al's (2006: 2183) study who have enduring pain, "sickness absence, its timing and duration [is] negotiated on the basis of the subjects' self-image, work-duty norms, organisational and extra-organisational work factors".

Boonen et al (2005: 400) discuss the impact of fibromyalgia on healthcare utilisation and lost work productivity, and note that, in their study, people with fibromyalgia "and CLBP[7] referred to a specialist express lower general wellbeing and are economically more costly than patients with ankylosing spondylitis". They conclude that the two conditions impair function of the individual in professional and private lives more so than ankylosing spondylitis. While hospital admission, alternative medicine and over-the-counter drugs costs were higher for fibromyalgia and CLBP, ankylosing spondylitis patients found the costs in terms of physiotherapy and prescription medication were more impactful (Boonen et al, 2005). For people involved in my study, both the management of healthcare utilisation costs and lost income due to absenteeism were challenging aspects of living with fibromyalgia. Exploring how people cope with the experience of fibromyalgia in light of workplace and familial obligations was a useful way of gaining insight into how these processes are shaped and handled by the individual and those they interact with.

Following Johansson & Lundberg (2004), Hansson et al (2006: 2184) describe the "illness flexibility model" which addressed the intersections of relations between "employees, workplace and social context" drawing on the employee's standpoint. The model is helpful in explaining sickness absence and attendance as it includes illness with reduced capacity to work as a premise of the perspective (Hansson et al, 2006). Hansson et al (2006) discuss "attendance requirements" and "adjustment latitude" and the distinctions and outcomes of the two concepts. "Attendance requirements" encourages sickness presenteeism through the knowledge that absence will lead to reduced economic earnings and increasingly accumulating workloads, as well as third-party involvement in cases where someone has to replace the absent person.

Where "adjustment latitude" is found, so too are opportunities for people with chronic pain conditions "to work despite illness. Adjustment latitude is what permits the ill person to moderate work according to current capacity" (Hansson et al, 2006: 2184). Within a condition like fibromyalgia where symptoms appear and disappear unexpectedly and accommodation of the experience is key to coping with and managing it, having a workplace

[7] Chronic low back pain

environment that has high adjustment latitude is critical. The experiences related in the interviews conducted for this study showed that workplaces were accommodating to an extent, but the uncertainty that marks fibromyalgia complicated this picture. This is explored further in the findings chapter of this thesis.

Practitioner-patient interactions

Interactions between practitioners and patients who have fibromyalgia are fraught with complexity, and as Dumit (2006: 578) describes, conditions that are emergent and contested are "illnesses you have to fight to get". As Barker (2008: 23) showed in her discussion of online fibromyalgia support group participation, the collective embodied expertise found on that platform allowed "participants [to] confirm the medical character of their problem and its remedy, and they search, as patient-consumers, for physicians who will recognize and treat their condition accordingly". Following Klawiter (2002), Dumit (2006) links this to the broader process of medicalisation, which is highly contested too. Klawiter (2002: 313), cited in Dumit (2006: 578) argues that this process requires "collective organizing and strategic claims-making across multiple arenas, and... a wide array of social actors". Furthermore, the medicalisation of conditions such as fibromyalgia is a process that occurs in degrees rather than absolutely, which results in one aspect or dimension of the condition or illness being more medicalised than others (Klawiter, 2002: 313 cited in Dumit, 2006: 578). It is in the interaction with a recognising practitioner that an individual's symptoms and experience will be given new meaning as they become categorised under the label of 'fibromyalgia'.

In the illness career, there are various stages an individual passes through with the hope to move away from illness and back towards health. Being granted access to the 'sick role' is both a medical and social encounter, with the one sphere affecting experience in the other (Dumit, 2006). This means that in being given access to the labelling of a 'disease' (through a clinical diagnosis), a person is granted access to the social 'sick role', where they are legitimately excused from 'normal' daily social life. They are additionally accommodated in their roles, behaviours and expectations in line with them being deemed 'sick', 'unwell' and therefore 'unable' (Cooper, 2002).

The process of moving through an illness career as a fibromyalgia patient is distinguished by the following stages: **searching for a diagnosis, pre-diagnosis, receiving diagnosis, post diagnosis, legitimacy and coping** (Sim and Madden, 2008). When diseases are 'socially invisible' or difficult to treat, movement through an illness career can be fraught with contestation and difficulty. This is because one not only aims to attain legitimacy for their experience, but also attempts to maintain it within a state of uncertainty and confusion. In the case where diagnosis for and treatment of the condition cannot be easily achieved, Dumit (2006: 577) notes that "institutional codes and doctor-patient interaction combine to produce 'symbolic domination'" in a context where "[doctors], government and insurance agencies appear to patients to be unable to hear their claims, denying them a social sick role".

Cooper (2002) discusses the notion of a stock of social knowledge and explains the ways in which it corresponds with medical knowledge. There are also concrete and symbolic ways that biomedical practitioners generally fulfil specific roles in terms of patients' illness careers. For Cooper (2002: 185) "the doctor [is] a figure of both symbolic authority within society and [is] a symbolic healer within our deeper subconscious". As demonstrated through this study, in cases when unsatisfactory explanations and prognosis of illness is given, patients challenge the authority and knowledge of these practitioners, as they are seen as not fulfilling their expected role (Cooper, 2002). People with fibromyalgia, in particular, experience rejection after the point of receiving a label. Most of the people involved in my study described how their practitioners said they had the condition, but there was nothing more that could be done for them. This is an example of the liminal state people with fibromyalgia enter having been diagnosed (Mendelson, 2009; Price and Walker, 2013).

Having access to a recognising practitioner who will take a holistic stance on treatment for the predicament of fibromyalgia was a critical step in the illness careers of the participants of this study. Salmon and Hall (2003) explored the shifts of responsibility from doctor to patient in cases of medically inexplicable symptoms, and the prominence of research that focuses on how patients cope with their illnesses. Whereas in traditional biomedical interactions, the practitioner is seen to work from a curative approach which leads to the successful resolution of an acute episode of illness. However, in the case chronic conditions with uncertain

aetiologies, such as fibromyalgia, this framework is too narrow to be applicable. Bieber et al (2006: 358) explain that,

> FMS patients often spend all their strength on struggling, quarrelling and asserting themselves during consultations and tend to use "war" and "legal" metaphors in their descriptions of medical encounters. The irritation seems to be reciprocal because doctors describe FMS patients as time-consuming, demanding, emotionally challenging, and draining. FMS can constitute a challenge to their professional identity since they are chiefly trained to manage clearly defined somatic diseases with objectively measurable physiological dysfunction. The uncertainty as to pathogenesis, diagnosis, and the lack of effective cures can elicit feelings of insufficiency, helplessness, guilt, and frustration. These negative feelings can cause doctors to want to withdraw from treatment by either limiting the amount of care provided or by referring these patients.

How a practitioner relates to their patient is particularly important when addressing conditions that are surrounded by so much contestation, and where patients are frequently at risk of delegitimation. Generally, practitioner communication serves three purposes, namely enabling good **interpersonal relationships; information exchanges; and making decisions regarding treatment** (Ong et al, 1995). The encounter of diagnosis frames the experience and trajectory of the patient as they move forward to the next steps of adapting to and accommodating their condition into their lives.

At this juncture, practitioners and the responses offered to the patients work in tandem to affect either positively or negatively on the subsequent experience of the condition. Within this interaction, the internet can play an important role of the internet in shaping medical knowledge. As demonstrated through this study, both patients and their practitioners relied on the internet as a flourishing source of information about fibromyalgia. Barker (2008: 22), citing Fox et al (2005) explains that the "widespread public availability of health and medical information alters the traditional doctor-patient relationship" and recreates the patient as a "reflexive consumer" who is active in the process of making decisions regarding treatment. This presents challenges when a knowledgeable consumer requests treatments and services "which fall outside established diagnostic and treatment protocols, [and] there is a risk of medicalizing experiences that would otherwise remain outside of medicine's purview, or intensifying the extent to which already medicalized conditions fall under the medical gaze" (Barker, 2008: 22).

From this, Barker (2008) asserts that the informed patient-consumer becomes an increasingly powerful force in how previously nonmedical conditions are defined and addressed in medical frameworks. The trajectory of fibromyalgia as a diagnosis illustrates this well, where a set of experiences that are subjectively felt, but are socially invisible, gained medical validity through the insistence of patients and the accepting response from recognising practitioners (Barker, 2008; Werner et al, 2003).For the participants of this study, interactions with practitioners fundamentally changed how they viewed their condition and the extent to which they were either enabled to seek management strategies, or veer into catastrophising and despair as a result of being stigmatised. This confirms the notion proposed by Stavropoulou (2011) that perceptions of doctors and the support offered affects adherence to recommended treatments. Stavropoulou (2011: 7) explain that the key points that led to better patient-practitioner encounters included "involvement in the decision making process, treating patients as equals and avoiding leaving unresolved issues when prescribing".

Thorne et al (2004: 299) assert that "patient–professional communication is a critically important element of effective chronic illness care. However, the dynamics of health care communication in supporting self-care management and effective coping with various chronic diseases is not well understood". The research undertaken here aimed to illuminate these interactions so as to inform practice further, especially in cases of contested conditions like fibromyalgia, and in contexts where little research exists on the subject, like SA. In coping with a condition as complex as fibromyalgia, the manner in which communication between patients and practitioners appears to be an important factor in determining whether patients continue to consult, or move on to form new relationships with practitioners perceived to be more supportive (Barker, 2008).

Schachna and Littlejohn (1999: 469) explain that,

> Fibromyalgia syndrome varies from being a mild intermittent disorder to one that is severe and protracted. Much of the management of the more common milder type is best done at the primary care level with the expectancy of improvement in key symptoms and a generally good prognosis. Careful appraisal of the dimensions of fibromyalgia is needed with an individualized management strategy. The primary care practitioner is well placed to identify

> risk factors that associate with fibromyalgia in order to minimize emotional distress accompanying illness or psychosocial predicaments.

Prior to attaining the diagnosis of fibromyalgia and after the label has been dispensed, while effective treatments are being sought, there are many discrediting opportunities that appear. This refers to the fact that the patient and their symptoms continually face challenges in gaining support, understanding, acceptance and explanation. Practitioners, in this regard, fundamentally shape the experience of the patient in coming to terms with living with fibromyalgia. The narratives collected for this study reflect the differential outcomes of patient-practitioner encounters and the ways in which the themes of recognition, legitimacy, support and care filter into this interaction.

Medical Aids and Bureaucracy

Maintaining legitimacy in the face of medical incomprehension is a process that must be managed carefully. In explaining the dynamics that shape this interaction, Potter and McKinlay (2005) note that patient education is necessary for time efficiency and efficacy, alongside developments in practitioners' communications with patients. Having said this, it is not either of practitioners or patients that need to change, "but rather the pressures and constraints of the organizational context within which the doctor-patient encounter takes place" (Potter and McKinlay, 2005: 465). Therefore understanding the constraints and opportunities presented by a particular context in terms of addressing a chronic condition like fibromyalgia is important. Benatar and Fleischer (2008: 433) explain that in light of medicine becoming increasingly expensive,

> resource allocation decisions need to be made and appropriate priority-setting processes developed. This challenge faces all societies but most agonisingly middle income countries like South Africa where the expectations of physicians and patients are geared to the best that can be achieved in any country — even the wealthiest. Expensive, new or established standard treatments that may benefit patients may be considered in at least two categories. The first is when each individual patient will be a direct beneficiary […] While such treatments have some mortality and a measure of sub-optimal results, good outcomes are the

> rule. The second category is when an expensive new or standard treatment is used to achieve a statistically demonstrable benefit for a patient population.

A challenge presented in managing fibromyalgia in the SA context was the two-fold issue of effective treatments and the accessibility thereof. McIntyre et al (2003: 48) explain that as a result of "risk-rating" there has been "substantial fragmentation of risk-pools within medical schemes, and [this has led] to scheme cover becoming increasingly unaffordable for high-risk individuals". As previously discussed, there is a level of practitioner recognition needed in addressing fibromyalgia effectively, from being able to legitimise symptoms to proffering treatments that actually alleviate symptoms. However, this process is also critically shaped by the opportunities and constraints found in working in a bureaucratised and increasingly privatised healthcare service that de-prioritizes chronic pain conditions like fibromyalgia.

As discussed earlier, there is an inequitable healthcare system that dominates healthcare provision and access in SA (Stuckler et al, 2011). It was shown through the study that this system has a tangible impact on the ability of participants to seek information, care, support and treatment from practitioners operating in this environment. The possession of medical aid or healthcare insurance (the terms are used interchangeably here) crucially changes the abilities of people in this study to gain medical treatment and manage their condition effectively. This process occurs alongside other factors related to chronic illness management and help-seeking behaviour.

While this study did not focus particularly on medical aid use, in the narratives presented, there were clear changes in behaviour, specific strategising that occurred in light of medical aid coverage, and the access granted to private healthcare through this tool (McIntyre et al, 2007). The emergence of this finding was also an indicator of the context in which this study took place. The private-public divide and disproportionate availability of practitioners between the sectors (especially specialists) meant that people who attained the diagnosis of fibromyalgia in this study had all done so exclusively in private healthcare settings (Mooney and McIntyre, 2008).

McIntyre et al (2007: ii-iii) explain the effect on healthcare utilisation of SA's two tier health system which is

> fragmented along socio-economic lines, with the minority rich accessing the private health sector for all of their care requirements and covered by private health insurance (medical schemes), and the majority of the population dependent on relatively under-resourced, tax funded public sector health facilities. The disparities in resources available to each sector, relative to the population that each serves have widened over the past decade. While resources for the public health sector have been relatively stagnant in real per capita terms, there has been a rapid increase in real per capita spending on medical scheme members. There are also massive disparities in human resources between the two sectors, with 1 specialist doctor serving less than 500 people on average in the private sector but nearly 11,000 people in the public sector. The public-private mix is undoubtedly the greatest equity challenge facing the South African health system.

Pither (2005: 50) asserts that "if pain services are to play the crucial role that they should in the management of chronic illness and symptom management, their integration and organization must be properly financed and supported". While pain clinics exist in SA, the vast majority of the participants of my study had managed their fibromyalgia through individual consultations with practitioners. They had also relied on tailored treatment regimes that encompassed pharmacological and non-pharmacological remedies, lifestyle adaptations and active knowledge seeking rather than clinical management of their condition. This reflects the flexibility required for the individual in accommodating and adapting to fibromyalgia in their lives (Raff et al, 2014). Being responsive and accepting that "what works" is better than rigid recommendations was an important component of overcoming fibromyalgia for the participants in this study. This study fills a gap in the knowledge of fibromyalgia in SA by showing the treatments and techniques used to reduce symptom severity from the perspective of the patient.

The study additionally reflects the discontinuities between the bureaucratic structures and relations that emanate through the interactions between patients, practitioners and health systems in addressing fibromyalgia. Timmermans and Almeling (2009) analyse the effects of objectification, commodification, and standardising on health outcomes, practitioner-patient encounters and knowledge forms. They make a compelling argument about the fact that formality and informality and the perceived benefits and detractions of each. Citing Stinchcombe (2001), Timmermans and Almeling (2009: 21) note that "under certain

circumstances, formalisms advance substantive goals much more efficiently than various informal arrangements".

Due to recent incorporation of fibromyalgia treatment into the medical system and healthcare practice of SA there are still many uneven applications of the recommendations associated with pain management in the context (Raff et al, 2014). This means that, while there is a "blueprint" of responses for fibromyalgia treatment, there is flexibility in how they can be interpreted and disseminated (Timmermans and Almeling, 2009; Arnold, 2010). Following Hafferty and Light (1995), Light (2000) and Frankford (1994), Timmermans and Almeling (2009) view standardisation variously as a disciplinary mechanism, a tool of bureaucratisation, and a dehumanizing process. While there are benefits in improving healthcare outcomes through professionalization and standardisation, there are also dangers posed by the unyielding application of recommendations that are at odds with the needs of a patient. These discontinuities are found in the acknowledgement that flexibility is needed in the treatment of the condition, but regulating responses for any condition is fundamentally an organising task.

The development of recommendations relies on the ability to predict outcomes and systemising these responses is a process of depersonalising and homogenising experiences. With fibromyalgia experience, as related through this study, the unpredictable prognosis of the condition means that expected routes to recovery are not in place. Furthermore, a reflexive, holistic approach, which has been found to be effective in the treatment of fibromyalgia, is contradictory to the standardisation necessary to creating policy recommendation and structural responses. Timmermans and Almeling (2009) explain that this process can be further complicated by the financial relations that dictate practice and treatment availability and accessibility. This was demonstrated by the case study of fibromyalgia in SA, where the intangible prognosis and variant symptoms meant that responses and recommendations for treatment had to be tailored in a fashion that accommodated the individual needs of people with the condition.

Where the support structure of proper medical coverage is unavailable or restricted, seeking medical help and financing the process becomes challenging. It can also result in changes in behaviour whereby the individual relies more on self-care than medical consultation (DeVoe et al, 2008 cited in Percheski and Bzostek, 2013). Percheski and Bzostek (2013) looked at the impact of changing family systems and healthcare insurance in America on healthcare utilisation. Having noted that many people in the USA access medical insurance for themselves and their families through their workplaces, Percheski and Bzostek (2013) assert that with shifts in family demographics and composition, there are gaps that emerge in the healthcare coverage of members. Importantly for this study, there are also inconsistencies seen in the extent and type of medical coverage offered through medical insurance for people with fibromyalgia and their families. This in turn affects their healthcare utilisation.

Percheski and Bzostek (2013: 2) explored coverage patterns among siblings, and explained that "non-uniform coverage among children means that parents must expend more time, effort, or money to navigate multiple health care systems on behalf of their children". This was also the case for the people interviewed foe my study. Some of the participants had to alter their healthcare utilisation in light of limited access to medical services through their medical aid because of other family members being prioritized over them. This was the case when the participants were children receiving support from their parents and when they were parents giving support to their children or other family members. What this entails is that there are both positive and negative impacts of family support on living with fibromyalgia.

Where access to medical coverage, treatments and practitioners is granted through the family's possession of medical aid, the individual is able to seek help and receive care. In scenarios where medical aid access is available for the individual through their family, but restricted because of the number of members and limitations of benefits, healthcare behaviours and out-of-pocket payments also occur (Percheski and Bzostek, 2013). This is also an example of the inflexibility of medical aids as an institutional structure that shapes healthcare interaction and utilisation. When benefit runs out because of one family member's healthcare utilisation, adaptation and strategising for managing costs has to be undertaken by the whole family. This was another way the family and the individual interacted and coped with fibromyalgia as an illness experience together. In doing so, they were manoeuvring

around the unyielding confines of medical aid coverage and accessing healthcare where it was possible.

This was demonstrated through this study on a practical level, as families were often involved in the process of going to doctors and managing payments for medical treatments. Families also internalise the tasks and responsibilities (particularly within the household) that the person living with fibromyalgia can no longer cope with when their condition becomes overwhelming (Werner et al, 2004). Gage (2013: 44) would identify this as an "explicit" form of the process as there is "direct sharing of emotional, logistical, informational, and financial support". Having understanding parents, partners and children plays a critical role in how the individual experiences their condition. The ability to accept the chronicity and permanence of the condition is impacted in a number of ways by the reception a family gives someone living with fibromyalgia. The capacity to adapt to the limitations imposed by reduced capacity and requirements of frequent rest is additionally affected by accommodating or disparaging family attitudes. The individual's ability to seek help through doctors and treatments is also shaped directly by membership in a family with medical aid access and sufficient benefit coverage. This is explored more fully in the discussion of the findings that emerged from the research process.

Social Support

An important component of living with a chronic contested condition like fibromyalgia is the ability to draw on social support. The functions of social support, and the effects on the illness experience of those with fibromyalgia, are discussed in the section below. Health as a concept is a continually changing and contested set of understandings that are influenced by social forces (Seymor, 1989). Seymor (1989) goes on to discuss how the individual meanings and understandings of “health” are varied and products of the society in which they live. The social structures and forces that affect these individuals through interaction will inevitably shape their perceptions of health and its meaning, as well as the actions they take to attain and maintain a positive state of health (Seymor, 1989). An individual's understanding and experience of health, therefore, is not merely an abstract state of wellbeing that encompasses

physical, mental and social aspects. It is also the concrete outcome of individuals' encounters with the social structures and forces at play in their environment.

Aggleton (1990) notes some of the criticisms of the official definitions of health, and attempts to move the concept away from reductionist understandings as found in the conception of health as the "absence of illness or disease". Aggleton (1990: 8-10) shows the increasing importance being placed on more holistic, positive and comprehensive notions of health, such as health as an ideal state or personal strength or ability. He views health from a multi-dimensional perspective, encompassing physical, mental, sensual, social, sexual, spiritual, environmental and societal health, and concludes that there is no single perspective that is wholly useful in explaining health behaviours and health care (Aggleton, 1990). While the biomedical model holds court within Western-influenced societies (including SA), it is simply one perspective that co-exists with others within the society. Aggleton (1990) explains that lay beliefs allow people to make sense of health information that comes from various sources.

Furthermore, he notes that "popular perceptions of health arise from the attempts people make to seek order where often there is... chaos and confusion" (Aggleton, 1990: 16). Aggleton (1990) cites Fitzpatrick (1984) in labelling these lay beliefs as syncretic as they are drawn from a varied and often contradictory range of sources. In living and coping with fibromyalgia, knowledge about the condition, and the sources that produce that information, are important shaping factors in the experience of the condition. Learning the parameters, forms and manifestations of fibromyalgia and other chronic pain conditions involves navigating through much chaos and confusion that is located in the uncertainty that surrounds the diagnosis and treatment of the condition (Åsbring and Närvänen, 2004). At the junctures of gaining a diagnosis and in seeking effective treatment, lay knowledge, support and advice accompany the individual through these processes.

The predominant perspective utilised in this study was the Psycho-Social-Environmental (PSE) model of health and illness. Much has shifted in the ways in which health is conceptualised, accessed and experienced in modern society. Despite this, the tensions

between the Biomedical (BM) and PSE models of health and illness are still evident, and affect the way people understanding and engage with their health (Nettleton, 2008). There are many elements of the biomedical approach that are problematic. However, its influence in the sphere of healthcare and disease treatment, as well as the dominance of the approach in everyday habitual practices and attitudes towards health and illness, means that it can never be completely disregarded nor removed as a social structure.

The deeply ingrained influence and status of biomedical approaches to health and healthcare within society means that the approach continues to impact on the ways in which people understand and experience their health (Armstrong, 2000). The diminished influence of the biomedical perspective and explanatory framework surrounding contested conditions like fibromyalgia sets off an opportunity for other health approaches and knowledge to fit into the experience of the patient. This happens as they attempt to work their way through the confusion and complexity of being a chronically ill patient (Terhorst et al, 2011; Cunningham and Jillings, 2006). This also provides opportunities to explore these shortcomings of biomedical explanations, and allows for the alternative perspectives being utilised by people living with chronic pain conditions to be viewed and analysed.

The spaces where experiences, responses and practices are not sufficiently illuminated by biomedical explanations were a primary concern of the study undertaken and discussed in this thesis. As the biomedical approach has limited applicability to people with medically ill-defined conditions, it is this failure to identify or effectively treat their illness that sets the patient on a further path and quest for wellness. It further allows them to seek and utilise alternative perspectives and treatments (Sim and Madden, 2008). Through an investigation of the narratives of people living with conditions that are inadequately explained within biomedical frameworks, it was evident that a "restitution" narrative became impossible to use in the face of so much uncertainty. More frequently, "chaos" narratives were present as people with fibromyalgia struggled to confront their condition, find alleviating treatments and helpful explanations for their experience (Frank, 1997).

In drawing on societal support, which appeared in many forms and fulfilled a variety of

functions, people with fibromyalgia encountered a range of knowledge that either assisted or inhibited them in their illness career. As a key site of investigation and overarching theme of the research explained herein, it was important to acknowledge the extent to which biomedical healthcare is able to explain these conditions (Dumit, 2006). It was also important to understand the effect that these explanations have. In recognising their diminished role in the patient's illness career, it is noted that biomedicine develops particular responses in an attempt to reclaim and reassert its authority.

In the process of making sense of this conflicting and complex set of "knowledges", lay beliefs of health often have a powerful influence on the perceptions and actions that people approach health and health care with (Aggleton, 1990). This theme of knowledge, sources, and effects appears throughout the findings of this thesis. There is relatively little that is concretely known about fibromyalgia. Therefore understanding what information is available and where it comes from, as well how it is utilised by people living with the condition and those that they interact with in the course of their illness careers is useful.

Oliver et al (2001: 2711) explain that "patients with FM think about, talk about, and experience more pain than patients with rheumatoid arthritis (RA)". Part of the preoccupation people with fibromyalgia have around their health is the inexplicable symptoms they frequently experience. These symptoms are often overwhelming in their severity. For the person living with the condition; the confusion that arises in a context where the experience cannot be fully captured in conventional, expected frameworks like biomedicine is disconcerting (Sim and Madden, 2008; Barker, 2011). The comparison to RA is useful insofar as better biomedical indicators and explanations are available for the condition. This creates a differential experience based on recognition and legitimacy between RA and fibromyalgia, where the former's capacity to be incorporated and addressed within a biomedical perspective allows for clearer understandings of the experience than the latter. This in turn affects healthcare utilisation because fibromyalgia requires further searching and higher rates of medical consultation to explain and treat symptoms that are elusive and diverse in their character (Thomas et al, 2011).

The higher rate of healthcare interaction, as well as the process of attempting to come to terms with a medically inexplicable condition, means that people with fibromyalgia will talk about their pain when it is urgent and requires attention (Oliver et al, 2001). This will occur at a higher rate when the traditional route of help-seeking does not productively lead to a diagnosis that has clear enough parameters, as well as attached treatments, to account for the individual's experience. The process of seeking explanation and treatment is rarely undertaken by an individual alone. Families and peers are assistive in the support and knowledge they provide, which is present at every stage, seen both in the discussions with the ill person and the care extended in the process (Ell, 1996). This is the case with fibromyalgia, and it explains again why family and other sources of social support are important to view in presenting an account of the illness experience of the condition in SA.

For Wainwright (2008: 80) "the discourse of health cannot refer to a fixed set of beliefs and practices uniformly subscribed to by all, but must encompass differences and contradictions, varying not just between individuals, groups and places, but also over time". He also emphasises the changes that have taken place within the discourse of health, having moved from a unitary approach proposed by biomedicine to a more inclusive and comprehensive approach which views individuals in the context of their social norms, values and beliefs. These contradictions and complexities are evident in the SA context, as well as the way in which the understanding of socially constructed conceptions of health are changing. SA is a diverse society, on individual, family, community, spiritual, class and cultural bases. It has unequally distributed systems of healthcare, which correspond primarily with people's socio-economic status, but also intersect with race, gender and location (Chetty et al, 2012). These issues of access are further complicated by the contradictions between the biomedical discourses propagated by the formal health care sectors (both private and public), and the lay cultural and social beliefs people hold in relation to health and disease (Gilbert et al, 2010).

There are challenges faced in terms of capacity within the public healthcare system. There is also a lack of assimilation in language, culture and ideology between biomedical conceptions and practices of health and those held by the population, who in turn are attempting to understand the multifaceted and chaotic sphere of health (Gilson, 2003). Indeed, the definition of 'health' and 'illness' remains complex, contested and difficult to fully grasp. It

shows why lay beliefs hold great influence in understandings of health and help-seeking behaviour, and how this situation plays out in the specific conditions of SA. While there is diversity in the perspectives of health and illness available in the SA context, the hegemonic influence of biomedicine permeates many forms of lay explanations.

This is most especially seen in the case of internet-based information on chronic conditions like fibromyalgia (Hochlehnert et al, 2006; Lupton, 2013). Barker (2008: 20) explained that "the internet is now a principal source of health and medical information". Barker (2008) discusses consumer-driven medicalisation and the role of online support groups in the process of changing an essentially private experience of embodied distress into public discourse. Specifically Barker (2008: 22), citing Conrad (2005), considers the integration of lay expertise into the practitioner-patient relationship and the ways that "shifting engines of medicalization" are characterised by consumer "desire and demand".

In viewing the sources of knowledge drawn on by people living with fibromyalgia in SA, it was seen that there was a preference for internet-based information that had a strong presence of biomedicine in the content and tone. Internet-based explanations of fibromyalgia are readily available and easier to access than information from medical practitioners (Conrad and Stults, 2010). It was evident that many participants within this study consulted the internet to find meanings and explanations of their symptoms, before and after their diagnosis. Additionally, they frequently searched for treatments on the internet, and in the course of their browsing; they also encountered support groups that many of them found unhelpful. This is explored later in this thesis.

According to Wainwright (2008: 80), health discourse "refers to the totality of cultural norms, expectations and technologies through which a society understands and responds to illness". If an inclusive and holistic approach is taken with regards to the discourse of health, as noted above, then lay beliefs are effectively seen as coexisting with formal knowledges of health from a biomedical perspective. It also allows the navigation process of integrating these diverse and contradictory approaches to be more clearly understood. This was a useful approach for the investigations carried out in this study as the experiences of people living

with medically ill-defined conditions could be captured more comprehensively by adopting a holistic understanding of health and illness. The importance of personal views and beliefs in effective help-seeking behaviours and conceptualisation of health is discussed by Bury (2000). He notes the impact that lay beliefs can have on doctors or medical practitioners' imparting of 'knowledge'. Lay beliefs are not overtaken by the influential scope of biomedical science and its attributes. In fact, people continue to employ and rely on lay networks as they move through their illness experience (Lupton, 2003).

As these networks are sources of convincing knowledge (if not always empirically reliable) then their appeal is obvious as demonstrated by Bury (2000). The congruity between people's systems of health knowledge and their social perceptions, beliefs, norms and values all lead to lay beliefs around health issues impacting on the authority and dominance of biomedical knowledge within society. However, Barker (2008: 30) notes the complexity of this process and shows, in her study of fibromyalgia online support groups, that "through routine social interaction on the basis of very real (and yet very common) symptoms, the notion of a disease entity becomes reified, even in the absence of orthodox biomedical evidence… In the process of sharing details about their experiences with common forms of embodied suffering, they define and affirm the existence of fibromyalgia as a medical entity". This means that lay knowledge and sharing reinforces a diagnosis within a biomedical framework, and the experience, in Barker's (2008) view, is continually medicalised as biomedical explanations and treatments are sought. For people living with fibromyalgia in SA, this knowledge and the sources from which it was drawn continually shaped their experience of the condition. Furthermore, the sources and sites of knowledge were an integral part of the process of absorbing, reinforcing, contradicting and interpreting the information and advice offered by biomedicine and its practitioners in the course of their illness career (Conrad and Stults, 2010).

These surrounding sources and the knowledge they provided were an important space of making the experience of a contested and medically and socially invisible condition "real" and legitimate. Barker (2008: 23) discusses the fact that the inability of biomedicine to account for medically inexplicable experiences drives "an effort [by lay people] to provide answers and solutions to their problems that are consistent with their subjective experiences,

[and in this they] become "citizen scientists" or "patient experts" on their own behalf". For two of the participants of this study, the opportunity to revise symptoms and experiences in the explanatory framework of fibromyalgia was found in the discussion space created by family, peers and other knowledge sources, such as the media. In encountering the label of 'fibromyalgia' through their peers and the internet, in particular, they were able to reassess their symptoms and self-diagnose with fibromyalgia, as the descriptions, mechanisms, and manifestations of the condition made more sense to them than their present diagnosis (Sharf, 2006; Barker, 2010). This is discussed further when presenting the findings of this study.

The family, as a source of knowledge around health issues, also plays a crucial role in how individuals are socialised into their health and illness beliefs and behaviours and are a vital part of the lay referral system (Giddens, 2006). The family is integrally influential in the individual's health experience and illness outcomes. Their influence emanates from the fact that they are a powerful referential source of indicators regarding appropriate responses to illness and treatment. They are also often the primary and initial source of health and illness knowledge in fulfilling their 'popular' sector position (Gilbert et al, 2010).

For people living with fibromyalgia, they are also critical providers of support in coping with the experience of fluctuating symptoms. In giving care, empathy, knowledge and encouragement, the family can be seen to positively influence the individual in the course of their illness career. Conversely, stigma and derision that comes from family is seen to be seriously detrimental to the individual and their ability to come to terms with their condition and accept fibromyalgia as a part of their life (Werner et al, 2004, Åsbring and Närvänen, 2002). The value that individuals place in the opinions of their family shapes their perception of their condition, and themselves as a "sick" person, and has a tangible impact on their coping abilities.

This notion is supported by Oliver et al (2001) in their comments about the positive relationships that exist between social support and health outcomes. In comparing people with RA and people with fibromyalgia, Oliver et al (2001: 2711) explained that "functional measures of social support, particularly emotional support, have also been associated with

decreases in health care within a primary care setting". Practitioners are a critical ally in addressing and adapting to life with fibromyalgia. Families and peers additionally enhance the experience and coping ability of people with the condition. Within this understanding, it is important to account for these interactions and the impact they have on the illness experience of fibromyalgia. This is done in order to comprehensively explain the dynamics that shape this complex, contested condition. In looking at the sources of societal support and the knowledge offered through these interactions, the manner in which people with fibromyalgia in SA are able to draw on practitioners, family, peers and the media (particularly the internet) in the course of their illness career was explored.

Alternative forms of healthcare knowledge were frequently drawn upon in addition to the medical advice and support offered by practitioners. The approach taken by many participants in the study was an assertion that the knowledge being used simply had to work to be preferential. There was also little evidence that background or belief played a role in this process. These forms of healthcare knowledge and treatment are not particularly indigenous to SA, but as the country integrates itself into an increasingly globalised world, so too will knowledges 'travel' and create trends within contexts where they have no claim to be 'traditional'.

Broom, Doron and Tovey (2009) explain that the adoption and movement towards Complementary and Alternative Medicine (CAM) in many developed, specifically Westernised societies signals the departure from the central role biomedicine has played in people's understandings and experiences of health and sick-care. For Broom et al (2009: 699), "this emergent pluralism has been viewed as reflecting a 'cultural turn'... situated within a broader waning in public scientific knowledge and an increasingly individualized and subjectified cultural landscape, characterised by reflexivity... and scepticism toward expert knowledge". They further discuss the 'outsider' role that CAM fulfils in the way it is viewed by biomedical healthcare approaches, both at ideological and service provider levels.

As discussed earlier, patient education is a core part of treatment for fibromyalgia. In reducing the frequency and amount of healthcare utilisation, societal support has an important role to play in this process. The study by Oliver et al (2001) aimed to explain the impact of

social support and education on fibromyalgia experience, and they found that through their intervention, utilisation of healthcare services decreased and patient self-efficacy increased. For Oliver et al (2001: 2718) the complexity of the condition is linked to the "variety of symptoms associated with FM, the tendency for symptom severity to fluctuate, and the lack of a clear biological cause [which] creates difficulty in knowing what to address within the treatment component of a behavioral intervention". Therefore, enabling a patient to understand and be knowledgeable about their condition, as well as encouraging them to regain control of their experience through social support and education interventions effectively accounted for many of the challenges faced in addressing fibromyalgia (Oliver et al, 2001).

Families provide practical and emotional support for people living with fibromyalgia. In the study discussed in this thesis, the financial and personal care afforded to people with the condition through their families was an important finding to emerge from the research process. The family as a social institution could importantly be seen as a site of shared resources and knowledge in matters relating to health and illness (Ell, 1996). Citing Brody & Simmons (2007), Bousso et al (2012, 92) describe the balances of responsibility and attention that are required in maintaining "the "normal" functioning of the family system… and the family's financial needs, including health coverage" while providing palliative care and treatment for a seriously ill child. In their study of terminally ill children and the care provided by families in their homes in Brazil, Bousso et al (2012) discuss the fact that health care professionals hold authority in determining end-of-life decisions.

They assert that "family participation in the decision-making process is still negligible" in this context (Bousso et al, 2012: 92). While fibromyalgia as a chronic illness is not nearly as life-threatening, there is similarity in the trend for care to be relocated from health services into the home and family. There is also overlap in the effects of this process for both the people living with the condition, and those that support them. Bousso et al (2012: 94), citing Yantzi, Rosenberg & Mckeever (2007), Hays et al, 2006), Misko & Bousso (2007) and Dumont et al (2006), explain that caring for person with a life-threatening condition and the "long-term chronic implications" associated with the experience in the home places physical and emotional stress, strain and exhaustion on parents, grandparents and siblings. While felt

to a lesser degree in the experience of fibromyalgia, within a family system there is need for the person with the condition to be cared for and supported.

The family is generally the first port-of-call when illness is transformed from an internal, subjective experience into an external, interpreted issue. Symptoms are related and assessed for their severity and meaning and decisions of seeking further help or practicing self-care are primarily made within the context of a family. Furthermore, once medical help has been sought, a practitioner has been consulted, and treatment was prescribed and dispensed, the illness experience of the patient is played out in the presence and with the influence of a family system (Dumit, 2006; Giordano and Lindstrom, 2010). The involvement of the family in this regard exerts pressure, and can lead to strain being felt by the carers of someone with fibromyalgia (Lonardi, 2007; Skuladottir and Halldorsdottir, 2011). For the participants of my study, there was a fear that they were being a burden on their family and, as far as possible, they attempted to mitigate the pressure by undertaking self-care and responsibility for their state of health.

Despite this, they recognised the integral effect that their supportive family members and partners had on their experience of fibromyalgia. Care from family was indispensible in managing the condition, both in ensuring access to treatment as well as alleviation from family and household duties. This confirms the findings of Werner and Malterud's (2003) study on fibromyalgia where familial support either enhanced or worsened the experience of fibromyalgia for the individual in very tangible ways. Speaking about the "work-life balance", Bryson et al (2007: 1143) explain that there has been little research that focuses "on the relationship between employment, family work, stress and health, nor on the strategies for managing potential health effects".

Additionally, the role of social support in either enhancing or worsening the experience of the condition was an important finding that emerged in the research process. After the event of the diagnosis, and in receiving and making sense of the label of fibromyalgia, the family has an important role to play in the ongoing process of coping with the condition. Family members are prominent in the illness experience of fibromyalgia as they provide various

forms of fiscal and emotional support for the person with the condition. As Gage (2013: 44) argues, "social networks diffuse health-related resources, including information, strategies for managing care, emotional sustenance, and logistical support".

In enabling the individual to adapt to the demands of fibromyalgia, families are a consultative source of information, opinions and health practices. They also serve as base from which the individual is able to make sense of their condition. Given the proximity and intimacy shared between the individual and their family members, this source of knowledge is powerful and interaction occurs continuously (Giddens, 2006). Particularly for people with fibromyalgia, the family is important for the perception of illness and responses to symptoms. Recognising when the condition is unbearable, overwhelming and manageable, and when it is possible to push oneself past the discomfort and continue with daily life, is a component of coping with the condition that is strongly influenced by the family (Werner and Malterud, 2003).

Attaining the diagnosis of fibromyalgia and responding to symptoms, accessing treatments and medical insurance, is closely related to the social capital of the individual with the condition and their family. This is another example of Gage's (2013) assertion that health behaviour is explicitly shaped by social network interaction. Gage (2013: 44) explains that "individuals' social networks may contain beneficial social connections that help them gain access to health-related information, advice from a specialist, information about treatment options, connections to second opinions, or institutions that offer illness-related support". For Giordano and Lindstrom (2010: 700), citing Putnam (2004), social capital is "defined as the "social networks and norms of reciprocity"… [And] is considered a subset of social cohesion".

Within this, there is a strong relationship between trust and social participation, which mirrors the history and trajectory of social capital as a concept. In describing the relationship between social capital and health outcomes, Giordano and Lindstrom (2010) explain that higher levels of trust encourages the development of social networks, and social and civic participation, which is known to influence health outcomes. The promotion of trust between the individual and their family and social networks, as well as with healthcare practitioners

encountered in the course of their illness experience of fibromyalgia, was a tangible theme to emerge in the findings of the research undertaken here.

Giordano and Lindstrom (2010) explain that inequalities in health outcomes are intricately linked to socio-economic factors. They also link worsening health outcomes in this regard to diminished social capital, particularly in relation to interpersonal trust (Giordano and Lindstrom, 2010). The capacity to speak to and rely on people in one's social network was an influential factor in shaping health outcomes in fibromyalgia experience. The sense of isolation that often accompanies chronic illness (either inflicted or self-imposed) further highlights the need for a supportive social circle that will enable the individual to cope with their condition and manage it effectively (Dumit, 2006; Glenton, 2003).

An aspect highlighted through the research findings of this study was the ways in which people that have fibromyalgia provide support to others, who also have the condition. A trend emerged whereby those who had had the condition for a number of years, and were mostly managing their fibromyalgia, were able to give information, advice and support to those who had recently acquired the diagnosis. As Gage (2013: 44) states, "social networks, especially those between patients, may play a role in shaping individuals' conceptions of their role in their own care, and their perceptions of health care experiences". Gage (2013) notes the fact that consultations with practitioners have become shorter and depersonalised. For this reason, patients may come to rely on their social networks more readily for information, advice and resources related to managing their illness conditions. Citing Suitor & Pillemer (2000) and Thoits (2011), Gage (2013: 44) explains that

> because they have [firsthand] experience knowledge of the experience of coping with a particular life event [like adapting to fibromyalgia], experientially similar others can offer empathy and tailored emotional support… [They are also] thought to offer tailored active coping assistance, through exchange of information, ideas, resources, and strategies for getting the most out of their health care.

As mentioned, many of my study participants had been referred to practitioners through their social networks. The participants were able to draw on support and resources from their

social network, in order to find a practitioner who could recognise and respond to their inexplicable symptoms. This happened because either their peers knew someone who had fibromyalgia, or their peers had struggled with attaining the diagnosis themselves. Gage's (2013) assessment of the manner in which experientially similar people were able to provide support in ways that were adaptive to the needs of their peers in their network was also evident in the narratives collected through my study.

The participants of my study were instrumental in providing social support to others who had recently been diagnosed. They enacted this by recommending practitioners, treatments, modifications to diet and activities, as well as being an outlet for the emotional and psychological strains associated with living with a chronic condition like fibromyalgia. The internet additionally constituted an influential source of information for the participants of this study. People in the study found the internet useful for illuminating the diagnosis and options for treatment, as well as stories of experientially similar others, and they consulted the internet both before and after they had attained their diagnosis (Conrad and Stults, 2010).

The internet performed a number of functions for the people of this study. Before diagnosis, information found on the internet directed people to perceive their symptoms as being characteristic of fibromyalgia (Barker, 2010). Encountering the label in an accessible platform like the internet allowed the participants who utilised this information before diagnosis to make sense of their experience, and begin to believe it was real (Price and Walker, 2013). This was particularly important for three of the participants of this study, who had self-diagnosed with fibromyalgia, and who were using the label with information supplied by the internet (Tang and Ng, 2006).

Searching for meaning was a common feature of many of the narratives, and using the internet and information found there allowed participants to bolster their explanations and gain support for their experience (Dumit, 2006; Powell et al, 2003). Having received their diagnosis, participants then went to the internet to find further information that was not offered by their diagnosing practitioner. Furthermore, in attempting to find the parameters of the condition and treatments that were effective in alleviating symptoms, the internet proved

to be a vital resource in offering a range of options and perspectives to people living with fibromyalgia. This is discussed further in the findings chapter of this thesis.

Stigma

Stigmatising encounters had a profound impact on the participants of this study. The risk of being discredited is a fundamental component of stigma, as the individual becomes marked by difference, and this is critical to understanding experiences of chronic illness (Åsbring and Närvänen, 2002). Scrambler (2009) described the enacted and felt components of stigma, and the effects of concealment for avoiding or encountering stigmatising relations. Citing Charmaz (1983), Åsbring and Närvänen (2002) show how the lack of external, visible signs of symptoms and biomedical indicators result in the individual being diagnosed with mental, rather than physical, illness. This is frequently the case for people who live with chronic inexplicable pain, and investigating the misinterpretation of symptoms in fibromyalgia experience was a central aim of the study undertaken here. Nielson (2010: 4) notes that the "lack of diagnosis and a clear treatment path, combined with the open-ended nature of chronic pain, also meant participants [in her study] could not perform the roles of the socially acceptable sick person… [which lead to the person] being alternatively, if not explicitly, labelled as somehow different or difficult".

In fibromyalgia experience, the appearance and disappearance of symptoms is a discrediting aspect of the condition, as the predictability around expectation of the illness is lost (Nettleton, 2006a; Dumit, 2006; Larun and Malterud, 2007). For people living with the condition, the fact that symptoms disappear means that concealing and managing disclosure of diagnosis is possible. For many of the participants in this study, it was preferable to remain silent about their condition as a result of felt stigma. The concept is socially constructed and as such, it is subject to the social forces, structures and actors present in the context in which it is conceptualised and utilised (Scrambler, 2009).

Additionally, there is variability between and within contexts over space and time in how the concept is explained and expressed in specific social situations. Due to this capacity, the

concept is multi-dimensional, but it is also often contested and complex in nature (Stuber et al, 2008). 'Stigma' as a concept is often used in conjunction with others such as 'prejudice' and 'discrimination'. It is defined by Williams (1987: 135-136) as a "ritual" polluting of any "condition, attribute, trait, or behaviour that symbolically marks the bearer as 'culturally unacceptable' or 'inferior' and has as its subjective referent the notion of shame or disgrace".

Cohen et al (2011: 1639) citing Link and Phelan (2001) see stigmatization as characteristic of power imbalances, "whereby a dominant group becomes motivated to maintain the *status quo* in relation to those who are stigmatized, an action that can have important ethical, political, economic, and socio-cultural repercussions". As discussed earlier in this chapter, fibromyalgia as a diagnosis directly challenges medical knowledge and practice, as well as the professionals that hold authority in medical encounters, namely doctors. The result of these challenges is not the adaptation, but rather the rejection, of fibromyalgia and other chronic pain disorders from biomedical view (Barker, 2011; De Ruddere et al, 2012). This casts those who live with these conditions out into a sea of contestation and confusion, and creates difficulties in accessing effective explanations and treatments in overcoming the symptoms associated with the illness.

In confounding medical explanation and treatment, chronic pain and fibromyalgia in particular occupy an insecure position in medical discourse. There are some components of the illness that are biomedically visible, which lends legitimacy and acceptance for conditions and people with pain as features in the illness experience. Having said this, the discrediting potential of an incompletely biomedicalized condition (such as fibromyalgia) is high. This pushes people with these conditions into a precarious void of simultaneous accommodation and rejection (Nettleton, 2006a; Dumit, 2006). In the case where symptoms are normalised by the individual and society, there can be the dual challenge of having to assert the extraordinary component of the experience, which in turn creates opportunities for disregard and disbelief (Richardson, 2005; Jackson, 2005; Lonardi, 2007).

Conditions that are stigmatised also drive particular behaviour in relation to internet usage for knowledge seeking. Citing Berger, Wagner, and Baker (2005), Conrad and Stults (2010: 183)

explain that "those with stigmatized illnesses [like fibromyalgia] were statistically significantly more likely to use the Internet to obtain health, communicate with health-care practitioners about their conditions, and apply the information they had found to increase their utilization of health care". The effects of stigma on the experience of fibromyalgia in SA were evident in the narratives collected for this study. People with the condition faced continual scepticism and rejection from practitioners, employers, family and friends on the basis of their illness, and the potent stigmatising potential found with contested conditions like fibromyalgia. Unpacking the experiences and outcomes of these interactions within the questions of legitimacy, credibility, accommodation and support was a central aim of the study undertaken.

This chapter has discussed the relevant literature that informed the design of this study, and underpins the findings that emerged it. Themes such as legitimacy, credibility, diagnosis, chronic illness, prognosis, sickness, treatment, institutional responses, stigma and social support were all explored in this chapter. Detailed below is the methodology used in conducting this research.

METHODOLOGY

The main research question that guided the research process described in this thesis was "how is fibromyalgia as an illness experienced in the SA context?" Central to this research topic was the attempt to understand the complexity of this process.

As discussed in the rationale, studies that investigate the experience of people living with medically ill-defined conditions are distinctly lacking, most especially in the SA context. The research reported here used the narratives of people living with fibromyalgia as a case study. The research was conducted in order to capture the wider perspective of health and illness experience, behaviour, belief, social support and institutional interactions that exist around medically ill-defined conditions. The research undertaken herein was predominantly qualitative in approach. It was designed as an exploratory study, which aimed to give a rich and deep account of illness experience through a narrative analysis given by people living with fibromyalgia.

The study engaged with a variety of qualitative research methods; primarily in-depth interviews, diaries and secondary media analysis. The aim was to produce findings that broaden the current body of knowledge around illness experience, and bring insight into the particular experiences and navigating tools utilised by people living with medically ill-defined conditions in the context of SA (De Vaus, 2001; Weiss, 1995). Below is a detailed explanation of the research approach, sampling, methods and instruments used in this study, as well as the data analysis techniques employed. Additionally, there is a description and reflection on the limitations of the study, and an account of the ethical considerations involved in undertaking this research.

Narrative inquiry as a methodological approach

Attaining a perspective from the person at the centre of the processes of diagnosis, prognosis and treatment is vital when investigating illness, especially around conditions that have subjective components of experience. Keikelame and Swartz (2013), in their study on epilepsy in SA, discuss the role of stories in revealing how culture shapes illness experience and behaviours. Through the illness narrative of people living with chronic conditions (like

epilepsy and fibromyalgia), we can gain insight into the mechanisms and discourses the patient uses to construct a coherent telling of particular events and day-to-day experience of the condition. The formation of the narrative also constitutes an important part of the illness experience, in that opportunities appear in the telling and retelling of events, symptoms, stories and sufferings. In this, there is provision to interpret and articulate aspects of the experience in different ways from various perspectives (Keikelame and Swartz, 2013; Botha et al, 2002).

With conditions such as fibromyalgia, an illness narrative forms a central part of making sense of the condition; of accepting it as a part of their life. Following this, in the study undertaken here, narratives were a necessary and useful way of gaining insight into people's accounts of a complex, often hidden illness experience. Sools (2013: 94) explains that narrative inquiry covers "a rapidly expanding research field with diverse definitions, methodologies and approaches… and various disciplinary trajectories". Within health research, narrative inquiry has become a salient tool for exploring the accounts of people who experience illness in continuous, chronic forms. Privileging the lived experiences of people whose illnesses have low prestige in medical settings is a growing area of health research (Bleakley, 2005). It also crucially offers insight into processes, interactions and outcomes that are often hidden from empirical view. Furthermore, this narrative approach allows rich, descriptive data to emerge in a unique manner, in that the intersections of smaller, detailed stories reflects on larger, global issues that shape the health and illness experience in systemic ways (Sools, 2013).

As Nettleton et al (2004: 49) explains, "when a person's account is understood in its socio-biographical context…we can begin to gain an insight into the socially embedded, and possibly embodied, nature of people's experiences… the story reveals as much about the culturally available discourses as it does about the minutiae of the teller's life". Additionally, there is much to be revealed within narratives in relation to the language, ideologies, beliefs and representations available to those conveying the story of their illness. This is also reflective of the social values and norms that shape their understanding, interpretation and telling of their experiences (Nettleton et al, 2004 citing Hydén, 1997 and Bury, 2001).

Investigating **small stories** through narrative inquiry and analysis also allows the *sites* that are "typically [the] unofficial, marginal places where alternative stories emerge" to be bought

to the fore (Sools, 2013: 95). Understanding the individual experiences of people who live with fibromyalgia was a primary concern of this research. This was explored through an analysis of how they attempt to manage the condition, who they interact with in the process, and the broader impact of the social context they operate in. Following Riessman (2008), cited in Sools (2013), this research approach simultaneously sought to uncover both **big and small stories**. There are distinctions between the forms, in that big stories tell us *about* something, and small stories elucidate *how and why* an account appears in the way it does.

This study contains elements of both the content of the narratives as well as how they were able to emerge, and why they were appearing presently (Stanley 2008; Sools, 2013). For Stanley (2008: 436) narrative inquiry "provides a methodology, a set of broad procedural ideas and concepts, rather than a pre-set method or specified technique, and it encourages responsiveness to the dynamics of the research context". For these reasons, narrative inquiry was an appropriate and useful means of uncovering the perspectives of people living with fibromyalgia in SA. It also lent itself to the aims of reflexivity and partnership that were core elements in the research design of this study.

Description of research context, social dynamics and demographics of society broadly

SA provides a rich environment to study health and illness, and there is a distinct lack of knowledge and research about medically ill-defined conditions in this context. As Keikelame and Swartz (2013) note, there is insufficient research undertaken that specifically looks at illness experience in African contexts, and particularly when it comes to studies that use narrative inquiry as a methodological approach. There are many layers of inequality that characterise life in SA, and this is prominently shown in the structure of healthcare, as well as the access to and distribution thereof. While this is further elaborated elsewhere in this thesis, it is important to say here briefly that there exists a two-tier healthcare system in SA. The two systems experience disproportionate allocations of patients and practitioners between the public and private sectors (McIntyre et al, 2007; Stuckler et al, 2011).

Padarath et al (2003) discuss the fact that there are insufficient distributions of healthcare personnel along three key divides, namely that of public and private healthcare, urban and rural areas, and tertiary and primary healthcare provision. This hierarchy ensures that the best

care is found in private, urban and tertiary healthcare facilities where access is limited, and the burden of patients and incidence of illness is significantly lower than public, rural and primary healthcare settings. Additionally, as Mooney and McIntyre (2008:637) note, "the legacy of apartheid has meant that both health and health care are skewed along racial lines, and 60% of health care expenditure goes largely to the 14% of the population who have private health insurance". There is also a clear migration of practitioners along a "hierarchy of 'wealth' and result[s] in a global conveyer belt of health care personnel moving from the bottom to the top, increasing inequity" (Padarath et al, 2003: n.p). The inequality found in healthcare is reflective of the broader socio-economic inequalities that determine differential outcomes in almost every facet of daily life in SA.

While this thesis will not focus extensively on SA's healthcare context, it is important to locate this study in the setting it has been conceptualised and conducted within. An earlier chapter went into more extensive detail, but it is helpful to note here that, when considering the sample that the study drew upon to gather information and data, particular dynamics emerged as a result of doing the study in this specific SA context. Chetty et al (2012) highlight some of these relations in explaining the challenges facing those aiming to diagnose and treat neuropathic pain (which fibromyalgia is thought to be associated with) in SA. These include a lack of awareness and education among practitioners, including specialists, which consequently led to insufficient identification, assessment and management of neuropathic pain. Additionally, inappropriate treatments were dispensed and there has been an uneven adoption of a multidisciplinary approach to address neuropathic pain in SA (Chetty et al, 2012; Botha et al, 2002).

The purpose of the study undertaken here was not to offer a generalisable account of fibromyalgia. Rather, the aim was to gain more nuanced understandings of the experience through the narratives of a select group living with the condition (Barbour, 2008; Nettleton, 2006b). Linking these experiences to the SA context goes further than many other studies based in this environment, and makes a contribution to broadening knowledge on fibromyalgia through the perspective of the patient. Given the depth and richness of the data collected, there are opportunities for further investigation of the prevalence and impact of fibromyalgia in SA. However, encompassing a more general account of the condition was beyond the scope of this study.

Chetty et al (2012), like Padarath et al (2003), also see the lack of trained personnel as a challenge, as well as the variations in patient access to care which run along rural and urban and socioeconomic boundaries in SA. This is demonstrated by the example of the limitations of access. Once access has been obtained, it does not "guarantee access to the most appropriate drugs, as financial and [supply chain] constraints, and restricted formulary in the public sector and restricted reimbursement in the private sector limit access to appropriate medications" (Chetty et al, 2012: 312). This last factor is illustrated clearly through my study, in that access to treatment, and particularly securing medication necessary for chronic relief, became a salient issue across my study population. Fibromyalgia as an illness experience requires much investment - financial and otherwise - on the part of the patient, the practitioner, and the healthcare systems they interact with.

As Chetty et al (2012: 312) explain, the costs of neuropathic pain are extensive "with misdiagnosis, mistreatment, and mental and physical comorbidities such as depression and nerve damage contributing to the cost, in addition to usual diagnostic and treatment costs". Furthermore, combined with a reduction in ability to work and increased medical expenditure, "it has been reported that patients with [neuropathic pain] have annual healthcare costs threefold higher than the costs for matched control populations" (Chetty et al, 2012: 312). This was confirmed by the participants in my study, through their telling of their interactions with practitioners and medical aid schemes. As discussed below, the sample selected from the SA population is not reflective of the general demographics of the country. Rather the health opportunities are presented according to the inequitable ways that society and healthcare is structured in this context (Stuckler et al, 2011).

This means that the people who are able to seek help and discover the diagnosis of fibromyalgia, in their attempts to 'get better', have access to the upper end of the hierarchy of healthcare distribution, which also indicates their socio-economic position in the SA context. For this reason, as expanded upon later, talking to people from this background can give the impression that they are the population most affected by fibromyalgia and other MUS. However, this is not the case. As alluded to already, in the SA context, due to the dynamics and structure of the society, only those at the upper end of the socio-economic hierarchy can get to see the number and range of specialists needed in pursuing and clarifying the diagnosis of fibromyalgia (Namane, 2013). In attaining the diagnosis, people with fibromyalgia in SA demonstrate that they have ability to access private and specialised healthcare on the societal

level. They also have the tenacity to seek a constantly clearer explanation for their ailment on the personal level.

This is due to their cultural background, in recognising their symptoms as a condition that requires attention, as well as the financial resources that allow them to see many practitioners and press for more certainty in the explanations they are offered (Nettleton et al, 2004; Botha et al, 2002). It might also be due to a host of psychological variables that push people towards seeking meaningful answers to their condition. All of these factors are beyond the focus of this study. However, this study could provide the stimulus for further research on some of these aspects, such as the explanations drawn on by people living with fibromyalgia, and the interactions that shape the experience. The above means that although the condition of fibromyalgia appears disproportionately in groups of people who have high social status and wealth in SA, this does not imply that the experience of the condition is exclusive to this population (Basu et al, 2012).

Possibly the low rate of diagnosis commonly associated with the condition in public health settings means that, while people may have fibromyalgia, they have not yet encountered the label. The health knowledge, behaviours and resources needed to recognise the symptoms as illness, and seek treatment, will require higher levels of personal and fiscal resources than most South Africans have. Furthermore, the inequitable distributions of practitioners and facilities in SA, with the majority of specialists operating in the private healthcare sector, means that coming to the diagnosis is an arduous process, and rare as a result (Namane, 2013; Mooney and McIntyre, 2008). Although these issues are discussed in greater detail later in this thesis, as they impinge on the illness experience of fibromyalgia, this study's prime concern is not with the social distribution and representation of fibromyalgia in SA. However, this could be a useful topic for future research.

Sampling

The majority of participants in this study were individuals who, at some point in their illness career, had been diagnosed with fibromyalgia; either solely, or co-morbidly with other conditions. Two of the people interviewed had self-diagnosed with fibromyalgia, and they were included in the study because of the way in which their narratives fitted within the

complex picture that emerged during the course of this research process. The variety found in symptom experience, illness trajectory, and treatment options was of particular interest to this study. Consequently, accounting for this spectrum of experiences through a diverse population was very important. Research participants were viewed in this study as research partners following the IIDS Website (2010) definition (cited in Cooper, 2011).

Participants were seen not just as informants that provide data to be analysed. Rather it was viewed that there was the prospect offered of making sense of their experiences and encounters with medically ill-defined conditions (Cooper, 2011). Many of the people who participated in the research process saw the interview as an opportunity to be heard, which was important in light of all the scepticism they had faced in the course of their illness career (Frank, 2010). The research was reflective and reflexive in its design and execution, so that participants could be made aware of the processes they were subject to in their everyday experience, through their involvement in the study (Barbour, 2008). Through their participation, these people were offered insight into their experiences, at a conscious level, through the explanations provided in interviews and diary entries. The participants were given ownership of the information, moments to reflect and analyse the findings with the researcher. They will also have access to the thesis in order to advance their opportunities of gaining social and medical recognition, and legitimacy, for fibromyalgia.

In undertaking these commitments, the participants were able to understand themselves and their experiences more fully, and this transformed them from simply being participants to becoming research partners (Cooper, 2011). Fibromyalgia is a notoriously difficult diagnosis to attain, and so there were a variety of methods used in drawing participants into the study, as elaborated upon later. Participants in this study were drawn from a broader population that aligned with particular socio-economic backgrounds, lifestyle choices, and understandings of health and illness.

It is clear, from the group of participants I was able to access, that fibromyalgia as a diagnosis does not emerge in public healthcare settings (Chetty et al, 2012; Namane, 2013). This is contextualised by the acknowledgement of the structure of SA healthcare, and the dynamics that determine access to practitioners, facilities, and treatments as mentioned earlier. It takes persistence and multiple consultations, with costly tests that are unavailable to patients without access to private healthcare, to attain the diagnosis of fibromyalgia. For this reason,

there are links between social identity and social position, and the recognition of illness, resources, access to medical diagnosis and treatment, as well as institutions that administer these interactions (Beer et al, 2012). This in turn accounts for the social characteristics of the final group of participants in this study.

I contacted 20 people and invited them to participate in the study. Once they had confirmed their interest in the study, over the phone or via email, I sent an information sheet (attached as Appendix 1) for them to assess whether they wanted to be part of the study. In asking people about their illness experiences and matters that were often private, challenging and sensitive, I wanted participants to be fully aware of what the process involved, and what they were being asked to do and share. When obtaining informed consent (see Appendix 2), people I interviewed were made aware of the general scope of the research, what would be required of them through their voluntary participation and, importantly, what the aims of the study were. Many of the people I spoke to regarded me as a sort of "expert", and as someone who would be able to bring their perspectives to a broader audience as a means of advocacy.

Therefore, it was necessary to clarify to the people I interviewed that I was a researcher, with limited knowledge of the condition of fibromyalgia, and that my interest was sociological and not medical in nature. Participants were offered the opportunity to withdraw from the research at any stage. Reflexivity on the part of the researcher was crucial in assessing the extent to which participants were comfortable and able to relate their experiences, without being affected, both by the process and because of their condition (Barbour, 2008). There is a further discussion of this under the topic of "instrument reactivity". In reflecting on the data collection process, it was a reality of conducting research that much care and flexibility was needed. This was because the participants were people who live with a condition that includes exhaustion as a symptom, and so their wellbeing had to be held as paramount in conducting the research.

Participants were drawn into the study by employing **snowball sampling** which was **purposive** in approach (Greenstein et al, 2003). The sampling method was useful and suitable for this study, as people drawn into participation were part of the broader social network of the researcher. Readiness on the part of the participant to talk about the experience of fibromyalgia and sensitivity on the part of the researcher was required. Contacting people with the condition through their peers, families and practitioners meant

that there was personal connection and time to ensure the participants were fully informed before taking part in the study (Barbour, 2008). This study was conducted by gathering data from narrative interviews held with people who had encountered fibromyalgia as a diagnosis at some point in their illness career. The research follows the approach of Weiss (1995: 137) where I, as the researcher, was both embedded within and apart from "the milieu in which the respondents live".

In seeking participants, I, as the researcher, had a number of encounters where people in my social environment could refer me to friends, relatives, colleagues and peers that they knew had fibromyalgia. In one instance, a participant referred me to a peer who had fibromyalgia who also subsequently joined the study cohort. This happened by discussing my research topic with family, friends, acquaintances and contacts. In having a similar background to many of the participants, having come to them through my social networks, I was able to establish good rapport and partnerships with them. However, as someone who did not live with fibromyalgia, I was dissimilar from my participants in that regard. In being "an outsider who needed instruction in the respondent's milieu", I was able to hear their perspectives, and learn how they lived with their condition (Weiss, 1995: 137).

Mentioning "fibromyalgia" and casually 'advertising' through my general conversations, that I was looking to talk to people with the condition, proved to be a productive means of gaining access to participants. Utilising social networks additionally allowed for greater connection to be built between my participants and me. Furthermore, many of the concerns I had about interviewing people who were ill and vulnerable could be reassured by the fact that the participants came to be involved in the study through their peers, family, workplaces, colleagues and friends.

In addition, I also got in touch with a few practitioners to interview them as expert informants for the study. Of the three I contacted, only one was willing to be interviewed, and as a leading advocate of fibromyalgia in SA, he was an excellent source of knowledge on the subject. He was able to speak about fibromyalgia globally, but also about the specific way the condition plays out and is addressed in the SA context. Having been interviewed for the study, Prof Meyer generously offered to distribute my information sheet to selected patients of his, a strategy that contributed to me gaining more participants.

Of the 20 people contacted to be involved in this research process, 15 were ultimately interviewed. Reasons for not participating in the study were varied. They included the perception that their experience with fibromyalgia had passed, and they had no desire to revisit what was a challenging and upsetting point of time in their life. Others felt that their symptoms were currently too overwhelming to reflect on and articulate the experience coherently. This was an interesting dynamic in the research process, one that became clearer in conducting the research. Through this, it was apparent that opportunities to speak about their illness experience aligned with the stage of the participant's condition (Barbour, 2008: Mik-Meyer and Obling, 2012). Their ability to articulate their experience was dependent on whether they had distance from their symptoms, insofar as they were not feeling them in an overwhelming capacity at the point of being interviewed.

The interviews served to reflect what their lived experience of the condition involves. This refers to the fact being able to speak about their condition required of the participants some considerable space from the apex of the symptoms. Specifically this means that they had to be in relative good health, and have mostly come to terms with having the condition. This was not an intentional outcome of the research process. Participants were not selected on this basis, but it appears that these are necessary components of being able to articulate the experience of an often difficult and disconcerting condition.

The demographics of the participants are as follows: they ranged in age from 23 to 59. Five of them were under the age of 30, four under 40, two under 50 and four under 60 (See table in Appendix 5 attached for further participant details). They were all women, and the 13 who had received the diagnosis of fibromyalgia, had done so more than two years prior to being interviewed. All had received their diagnosis in a private healthcare setting. The demographic makeup of the study sample reflects the earlier discussion on the skewed distribution of the diagnosis. As previously mentioned, the diagnosis of fibromyalgia is found almost exclusively through private healthcare services in the SA context.

While this gives a view of fibromyalgia as being a "disease of the affluent", it is important to note the resource and personal capacity it takes to attain the diagnosis as discussed earlier (McIntyre et al, 2003). It is acknowledged that the study sample is not representative of the demographics of SA, and is not generalisable due to the case study nature of the research (Barbour, 2008). Having said this, it is an important reflection of illnesses that require pursuit

and high interaction with healthcare providers and practitioners (such as medical aids, private healthcare facilities and specialist doctors) to attain the diagnosis. This study, through the sample dynamics, is reflective of the broader trends of fibromyalgia as a gendered phenomenon, with women disproportionately represented in the experience of the condition, as discussed earlier.

Two of the participants had self-diagnosed with fibromyalgia by searching the internet and through the lay referral system (Tang and Ng, 2006; Sharf, 2006). Both sources of knowledge, as well as families and practitioners, played an important role in the perceptions of the experience, and the health behaviours enacted in seeking treatment for the condition. The one man who was approached to be interviewed was unwilling to participate, as he did not feel it was necessary to talk about his condition. Among the sample, there were people who had experienced symptoms for as many as 20 years, with inevitable quests for diagnosis and continued searches for clarification of the explanations offered. All participants had experienced co-morbidity with other conditions, which matched the "spectrum" explanation of fibromyalgia (Paralikar et al, 2011).

Fourteen of the women were South African and one had a British background. Thirteen were white and two were coloured women[8]. Thirteen were English-speaking, two were Afrikaans, and all resided in urban areas of SA with the majority being based in Johannesburg, as well as Pretoria, Durban and surrounding areas (See appendix 5). Medical aid access was uneven among the sample as older participants generally had good access to medical care while younger participants were financially insecure and as a result had minimal or no access. Medical aid access is linked to the private/public health sector divide that exists in SA and is discussed elsewhere in this thesis. Without medical aid access and coverage, private medical care is prohibitively costly. The majority of practitioners and quality facilities are found in the private sector. Medical aid access was seen as a determining factor in attaining diagnosis and shaped the management of fibromyalgia for the participants in this study.

[8] The use of the terms "African", "Coloured", "Indian" and "White" reflects a statutory stratification of the South African population in terms of the former Population Registration Act. The use of these terms does not imply the legitimacy of this racist terminology. It is a necessary component to acknowledge the diversity of South African society and is used to describe groupings that previously had differential access to services, economic opportunity, education and healthcare amongst other resources. It is done to highlight the impact of former apartheid policies on various South African systems (Wadee et al, 2003: 4; McIntyre et al, 2007: 10)

The women were distinctly middle class, highly educated and qualified professionals, ambitious and driven and this matched the personality component of being "high achievers" as described by Meyer (2012). Arnold et al (2008) also characterised their participants as driven and discussed the frustration felt around lost capacity in line with what they previously knew they could do. In other contexts covered in the literature, fibromyalgia appears regardless of class and educational status but in SA, it is most visible among populations with high socio-economic status because of the structure of healthcare access in the country. Across all contexts, fibromyalgia is a gendered phenomenon with women being disproportionally affected by the condition. This was discussed in greater detail elsewhere in this thesis.

In SA access to private healthcare automatically ensures occupation in the middle-to-upper classes of society as those with medical aid are within the minority of the population as the schemes are costly and often inaccessible for most South Africans (McIntyre et al, 2007). In acknowledging this, the study reported herein aimed to capture as many aspects of the participants' social identity as possible and account for the overlaps between experience and social conditions of class, geographic location, cultural and religious backgrounds, and interpretations and perspectives of health and illness. Additionally the access they had to practitioners, facilities, institutions, workplace structures and private medical insurance schemes they interacted with in seeking treatment and attempting to adapt to fibromyalgia as a part of their lives.

In order to be inclusionary, this study did not aim to subscribe what the background of patients might be; rather it hoped to explain their experiences in terms of their social identity and the context in which their illness experience unfolds. Having said this, it is recognised that fibromyalgia, as a diagnosed condition, will appear in particular social circles. This is due the difficulty found in diagnosis, the "quest" that precedes and follows the attainment of the label, and the availability of treatment. In adopting an exploratory research approach, this research aimed to be broad-reaching, descriptive and reflexive in investigating the issues presented here and analysing findings that emerged (Nettleton et al, 2004; Timmermans, 2013; Thomas and Johnson, 2000).

Since fibromyalgia is a relatively unknown condition globally, and specifically in the SA context, finding participants for this study was a challenge. Therefore, I approached sampling

participants with much openness to allow as many people as possible to come forward. As already mentioned, all who had secured diagnoses had done so in private medical settings, often with the assistance of specialist practitioners. It is acknowledged that because of the narrow parameters of this sample there is a very particular picture that emerges from the findings of this research (de Vaus, 2001). However, in accounting for this, there is an important contribution to be made by this research for the field of health sociology in SA. This is due to the insight and novelty gained in this context in relation to the functions of health systems and medical aid schemes in SA, and the experiences of people living with conditions that have medical uncertainty attached to them (like fibromyalgia). Furthermore, this research gave innovative perspectives on the strategies utilised to seek help and restore wellness in the face of delegitimation and chronic illness in this context.

Data collection

The main body of data was collected through the use of interviews and diaries. See Appendixes 3 and 4 for the diary template given to participants, and the protocol used in the interviews. Both methods are most suitable for capturing insights into narratives that are detailed and nuanced, and move beyond the standardised, 'bulky' data found when using quantitative methods (Barbour, 2008). Semi-structured interviews were used, and a conversational tone was adopted so as to foster an environment where the participant's "small story" could develop as naturally as possible (Sools, 2013). Within a narrative approach, there is an attempt to capture a full story.

While directive questions were asked (see Appendix 4), the interview was loose in form and structure in that participants were encouraged to talk openly and freely, often straying from the central topics of the study (Nettleton, 2006b; Barbour, 2008). This proved to be an important route for garnering the narrative of fibromyalgia illness experience. Participants related various complexities that characterise and relate to experiences of conditions that are insecure and unpredictable, lack sufficient explanation and legitimacy from the medical community and appear in between and among a range of other illnesses. In telling stories from their lives, they also related the key events that characterised their experiences before, after and during their encounters with fibromyalgia and other illnesses (Whitehead, 2006).

By investigating seemingly scattered stories about their lives, this study was able to bring to light an explanation of the way fibromyalgia as an illness experience manifests in the SA context. This was done by looking at the institutions, practitioners, discourses, interactions, support networks, healthcare systems and the accessibility thereof, health beliefs and knowledge, through the narratives of the individuals that embody and experience this condition. A perspective that is often marginalised and neglected in the medical discourse and writings of health and illness is brought to the forefront through this study. It reflects the powerful ability of narrative inquiry to uncover rich data around complex and important issues, namely, what it entails to live with a condition like fibromyalgia (Nettleton et al, 2004).

Expert interviews were used as another perspective to sit alongside the patient perspective and document analysis of searches for internet information related to fibromyalgia. This triangulation process helped bolster the deeply descriptive primary data cultivated from the interviews, and created a lens through which the emerging picture could be more fully viewed (Sools, 2013; Bogenschneider and Pallock, 2008). Fibromyalgia narratives are located within a myriad of discourses, social processes, actors, institutions, policies and healthcare systems. Therefore, capturing a range of perspectives (professional and media namely) was enormously helpful in plotting a complete story.

Up to two interviews were conducted with participants throughout the research process, so as to initially understand their experience, before later interrogating their experiences more deeply in line with the collective body of narratives that emerged in the study. Four participants were interviewed twice, as their narratives contained issues that required further exploration. Most participants felt that they had offered as much as they could during their initial interview, and were unwilling to revisit their illness experiences that had often been characterised by trauma and discomfort. This part of the process generated 20 interviews, which were between an hour and three hours in duration. Permission to record the interviews was obtained by informed consent, and the interviews were later transcribed by the researcher and an assistant.

Four participants were prepared to keep a diary in which they recorded their thoughts, feelings, beliefs, interactions and daily lives following the interviews. While the diary was requested of all participants, many felt that they were not in a position in their illness career

to delve further into their encounters with fibromyalgia after the interview. This was because many of the people I spoke to had largely come to a place where they were managing their symptoms, and were invested with more pressing conditions. In other words, they were no longer searching for meaning in their illness experience, and they had accepted and were coping with the condition as part of their life. Therefore, the opportunity to reflect on a time in their life where they had literally and figuratively experienced overwhelming pain, disbelief and struggle was not appealing to them. The reactivity of the diaries as a research instrument is discussed below in the challenges of the research process.

The media content analysis undertaken looked at internet news articles from SA databases and covered the time span of 2000-2014. News articles were specifically used because they represent the most general, accessible level of information, where knowledge circulates among the broader population. The search terms of "fibromyalgia" and "South Africa" were used and articles were organised and coded by relevance using Nvivo10. The presence and prevalence of fibromyalgia as a label on these platforms indicates the trajectory that the diagnosis has followed over this time period. The types of information found in relation to the term offers an interesting counter-point to the debates of what is known about fibromyalgia and the forms of knowledge offered to those living with the condition.

The use of multiple research instruments allows for a more holistic investigation of the topic, as narratives cannot be relayed in a chance encounter, but rather as the continual process of lived experience. With a contested condition such as fibromyalgia, there is much movement in the way the person experiences legitimacy, acceptance, as well as relief of symptoms, diagnoses that are more concrete, support and care. This process reflects both the nature and treatment of the condition. Capturing these elements through the additional use of diaries, expert explanation and internet sites was useful, because it took into account more than the space of interview. It allowed the participant to reflect on their experiences and express their views in their own lexicon and language, and for that perspective to be cemented and confirmed through supplementary sources (Cooper, 2011; Greenstein et al, 2003). By investigating the "small stories" and attaching them to the "big stories", a dialectic process of exploring complex and rich data can ensue and bring to light, through narrative inquiry, a unique perspective of living with a chronic, contested condition (Sools, 2013).

Difficulties encountered in the data collection process

The biggest difficulty with this study was the fact that many of the people diagnosed with fibromyalgia were also diagnosed with other illnesses. Due to this, participants had often moved away from the diagnosis of fibromyalgia, and towards other conditions as the primary sites of concern in their illness careers. Fibromyalgia characteristically appears on a spectrum of other conditions. This simultaneously masks and makes visible the condition, in that the collection of symptoms is given unified meaning under the banner of Central System Sensitivity illnesses. However, pinpointing illness experience that is exclusively related to fibromyalgia then becomes challenging (Meyer, 2006). While the task of unravelling the narratives was complex, it was also rewarding, with many new and intriguing findings related to living with fibromyalgia in SA coming to light during the course of the research process. The sampling strategy for gaining participants for this study was inclusive. As long as the individual had encountered a diagnosis of fibromyalgia at some point in their illness experience, they were able to be involved in this study. This allowed for many valuable perspectives to be offered by the participants in the course of the research process.

Gaining participants proved challenging at times, as the condition has an almost 'hidden' or 'socially invisible' status in the medical scene of SA. This occurs because there are no formal advocacy bodies, few formal medical guidelines for recognising and treating fibromyalgia, and support groups are sporadic and loosely organised in their activities. While practitioners, in general, are aware of fibromyalgia, there is much surrounding scepticism, because of the uncertain aetiology and manifestations associated with the condition (Mik-Meyer and Obling, 2012; Barker, 2008). This issue was reflected many times in the participants' narratives, in the persistence it took to be diagnosed and continually treated, as well as the disconfirmation of diagnosis that a few of the participants experienced and related during their interviews.

Seeking participants was a sporadic process, and this was indicative of the isolated and invisible nature of fibromyalgia in SA. This meant that the people I accessed often had not spoken extensively about their condition, and how they lived with it. Some were reticent to share their perspectives, as their story of encountering illness, and fibromyalgia in particular, was a difficult one to relate, but by establishing solid and nurturing rapport with participants, most felt

comfortable talking about their experiences. Others felt that, through their participation in this study, they were being given an opportunity to illuminate and connect with a body of common experience that could be taken forward as an avenue of advocacy for fibromyalgia recognition in SA. This was not an explicit aim, and as the researcher, I frequently had to clarify my position and expectations for the scope of the study.

Having said this, many of the findings have applicable implications for the recognition and treatment of fibromyalgia in SA, and could be utilised as a tool in furthering advocacy for the condition in this environment through informing patients, practitioners, institutions and workplaces, as well as peers and relatives of those living with fibromyalgia. As Terre Blanche and Durrheim (2006) explain, when we collect data through interacting with participants, they are bound to be influenced by the way the study views a particular phenomenon, and by publishing the research, an explicit intervention is performed. This shapes "the way a phenomenon is understood but also the way in which the social practices that hold the phenomenon in place will be acted upon in the future" (Terre Blanche and Durrheim, 2006: 11). In acknowledging the potential for this research to set this process in motion, extra caution was taken to ensure clarity of scope and objectives for conducting this investigation.

The predominant form that fibromyalgia, in its symptomology, takes is overwhelming pain and exhaustion. This meant that in conducting the research, I had to be responsive, reflexive and reflective of the impact involvement in my study would have on the participants. The impact could be seen both in their capacity to talk extensively about issues and experiences which were in many cases deeply troubling for them. Additionally it was seen in the exertion required in talking for long periods of time. Flexibility was key in accommodating what my participants could cope with, and I made sure to account for their comfort and energy levels before and during the interviews.

Sensitivity was also required when probing for further explanation and a narrative inquiry approach was also useful in this regard, as it allowed me to broach topics that were often difficult for the participants to talk about by getting to them through a course of general, directed conversation. This set up an interview environment that enabled participants to feel comfortable

with talking to me, and allowed me to gauge the boundaries and limits of discussion easily, by seeing how far they were willing and able to share their experiences (Hydén, 1997). By being reflexive, the perspectives that came to light were refreshingly frank. Many of the participants commented, in feedback to the researcher, that they were pleased with the manner in which the interview had been conducted, and how much they appreciated speaking to someone who would hear their story, which often had never been extensively discussed before.

The diaries also presented a challenge to the research process, as they were a reactive instrument and were unpopular with the participants. Many were unwilling to return an experience that at times had been overwhelming, demoralising, traumatic and troubling. They felt that keeping a diary was unnecessary as they had largely overcome their illness, and had their symptoms under control. They seemed to view the diary as a step too far, in making conscious processes that they had largely experienced unknowingly while attempting to cope with the condition. Instead, participants were keen to look and move forward rather than reflect retrospectively. As all stages of the research process were voluntary, and while participants were given diaries after the interview, they were aware that there was no consequence for not keeping it. In one case, the thought of keeping a diary was actively distressing for the participant, as she felt she was going to have to go over experiences and components of her illness that were better left in her past and did not belong in her present reality.

Others felt that since they had resolved their experiences with fibromyalgia, it was pointless to delve further, while some simply felt they did not have the time or inclination to commit to the process of keeping a diary. All these factors were accounted for, and as much accommodation as possible was made for the needs and desires of the participants in ensuring their wellbeing in this process. It was emphasised that the diary was for their use, and it was up to the participants if they wanted to share their reflections with me. For those who chose to participate in this stage, it was an opportunity to interrogate more deeply issues, processes and encounters that shaped their illness experience. It also produced data of a more personal, detailed nature than the interview material. Those who kept diaries found the experience productive in reaching a new understanding of themselves and their condition. By bringing to light what they go through on a daily basis, they could also track what they had previously encountered, and could reflect on future paths they might take in seeking treatment. Fortunately, the interviews themselves

revealed an abundant amount of data that extensively described many aspects of living with fibromyalgia, and highlighted the unique challenges presented in experiencing this condition in the SA context.

As mentioned previously, the opportunity to speak to people living with a chronic condition was a serious matter of timing (Thomas and Johnson, 2000). There was a stark contrast in the perspectives offered by people at different stages of their illness career. Some people were at the apex of fibromyalgia illness experience, when symptoms were overwhelming, treatment was still being sought, and sense was still being made of the condition. Others had mostly overcome the condition, had assimilated the management of the condition into their lives, and were presently addressing other conditions, life challenges and experiences, rather than primarily fibromyalgia. Fibromyalgia as a condition often appears alongside depression and, in and of itself, the nature of fibromyalgia and the mismanagement of diagnosis and treatment by health systems, carers, practitioners and institutions, can be deeply distressing (Åsbring and Närvänen, 2004).

Very early on in my research process, I interviewed a young woman who had self-diagnosed with fibromyalgia, and had experienced extensive trauma and a range of illnesses in her life. The first time I met Jenna was on the day of the interview, and she opened up to me about her experiences, a process that resulted in me sharing events from my life in order to comfort her. What she told me was distressing for her to relate and for me to hear, however after the interview, I felt it was necessary to reassure her. In building on the rapport we established during the interview, I wanted to acknowledge and address what involvement in my study had brought up for her, the ways that it distressed her, and I wanted to mitigate those harms (Barbour, 2008; Weiss, 1995).

As my participants' wellbeing, and status as vulnerable subjects (insofar as they live with a chronic condition), was at the forefront of my mind while conducting this research, I broke protocol by getting involved. In telling her about my life, she was relieved and comforted. We were able to talk through what had happened in the interview in a way that heightened a sense of trust and friendship, which lasted beyond the research process. Additionally, I was able to take forward many lessons from that experience, namely to be cognisant of my own feelings and

reactions to things being related to me in a specific context, namely an interview (Ellingson, 2006). I learned how to deal with them, during and after the fact. It was important to place the wellbeing of my participants as paramount, and to acknowledge the reactive nature of my research instruments in provoking and reminding the people I spoke to of events and experiences that could hold elements of discomfort and distress for them. Following that, I had to be accordingly responsive to their needs and the effects of the interview on them. The greatest outcome of this process was that I was able to vastly improve the range and depth of my skills as a researcher.

Data analysis

Once the interviews had been conducted and transcribed, in-depth thematic analysis occurred. The sheer quantity of data that emerged from this research process ensured that data saturation was reached within the interviews, diaries and media content drawn through this study. QSR Nvivo 10 was used to manage and partially analyse the data along a broad coding frame (Price and Walker, 2013). The analysis is thematically organised, so as to identify and explore the particular issues that emerged across the narratives (Lee and Poole, 2005). In addition, the diaries were used as a supplementary tool to add texture and depth to the themes collated in the interviews. The data produced through this study also required the use of document and narrative analysis techniques, which are useful in explaining the perceptions, feelings, experiences and interactions of people living with fibromyalgia in a SA context (Luttrell, 2005).

Limitations of the methodology

While the type of data collected using qualitative methods is rich, thick and descriptive in nature, there is a limitation in the representative capacity of the information. The findings of this research may not be generalisable to the broader population, as is inherently the case in taking a snapshot, particular view of a social phenomenon (Weiss, 1995; Barbour, 2008). The use of the case study, in this regard, means that what is discovered in this research process might not be able to account for a bigger set of health and illness experience questions (Timmermans, 2013). Having said this, in reflecting a particular experience, it is hoped that insight into the wider

process, actors and institutions that shape health and illness experience can be gained (Sools, 2013).

Ethical considerations

Having submitted a formal application to the Wits Ethics Committee in November 2011, ethics clearance for this study (protocol number: H111139) was granted in early 2012. The study utilised informed and voluntary consent in drawing participants into the research process. Each participant was given a detailed information sheet, and briefed fully on the purpose and nature of the research detailed herein. Additionally, much care was taken to ensure that the wellbeing of the participants was considered throughout the research process, with sensitivity and reflexivity on the part of the researcher being used as tools to facilitate this. As Wassenaar (2006: 63) explains, "participants' dignity and welfare should always transcend the interest of the research". All participants, having received the information sheets before the interviews, were given the opportunity to withdraw from the research at any stage. Confidentiality was guaranteed to the participants, and anonymity through the use of pseudonyms was offered. Professor Meyer did not want anonymity and as an expert, key informant on the topic of fibromyalgia in South Africa, his name appears alongside his narrative. All other names used in this thesis have been changed in order to protect the identity of the participants. This includes the names of participants, their family members, friends, colleagues and practitioners.

Validity and reliability

The main limitation of this research remains with the inability to generalise beyond the sample of the study. According to Greenstein et al (2003), internal and external validity are crucial for drawing legitimate conclusions from research findings. The study reported on in this thesis has low external validity, as the findings cannot be seen to be generally relevant or extrapolated outside of the sample population. Having said this, there are many components of the research process that have been hugely successful, and are very replicable as a research approach and design. Additionally, the data garnered through this process has been rich, detailed and revelatory of processes, experiences and interactions that are important to acknowledge (Timmermans, 2013; Bleakley, 2005). The findings of this research could be

informative for practitioners, policy-makers, institutions and patients who encounter and attempt to address fibromyalgia (and chronic illness and pain conditions generally) in the SA context. This displays the high internal validity of the study, and by seeking perspectives from a range of sources (interviews, diaries, media content and document analysis, and expert informants), and producing consistent findings, there is also good reliability of the research design and the findings that have emerged (Greenstein et al, 2003).

Conclusion

This chapter has outlined the central methodological approach, methods employed and instruments used in conducting an exploratory study that uncovered the experiences and perspectives of people living with fibromyalgia in SA. By attaining their narratives through the use of interviews and diaries (in selected cases), the research effectively captured the processes of diagnosis, prognosis and treatment that a group of 15 women living in SA encounter in the course of their illness experience with fibromyalgia. A brief explanation of the dynamics and structures that shape healthcare opportunities and outcomes in the SA context was included, as studies like the one detailed in this thesis are rare in this environment. Through a reflection of the limitations, ethical considerations and internal and external validity of the research, it was shown that the study was reflexive in nature, and as far as possible aimed to treat participants as partners in the research process. The next chapter unfolds the extensive findings of this study, with particular attention being paid to how the various narratives (patient, expert, fibromyalgia discourse) interweave, clash and relate to each other in explaining the illness experience of fibromyalgia in SA.

ANALYSIS OF FINDINGS

This chapter constitutes the findings and analysis section of this thesis. In eight interrelated sections, the evidence gathered in this research process is unpacked and explained thematically, in order to understand the experience of fibromyalgia from the perspective of people living with the condition, in the specific social environment of SA. These findings primarily arise from the evidence and narratives found in the interviews held and diaries kept by the participants in this exploratory research study. Additional data collected through the media content analysis and literature explored for this study augments the themes of narratives, and helps with presenting a comprehensive perspective of the experience in this context.

The broader themes of legitimacy, credibility, articulation, recognition, support and care were used to explain the findings are continuously explored throughout the sections on **Fibromyalgia**, **Diagnosis** and **Explaining the Inexplicable**. The sections on **Prognosis**, **Sickness and the Illness Career** unpack the discrediting effects of fibromyalgia as a broad category of pain and exhaustion. The difficulties faced in finding the parameters of an unpredictable condition, as well as the challenges of developing flexible responses, are discussed in those sections. Finally, in this chapter, the experience of fibromyalgia is expanded upon by investigating the role of **Treatment**, **Institutional Interactions** and **Social Support** in managing the symptoms of the condition. By understanding the means and mechanisms that shape better or worse outcomes for people in coping with the experience, the central role of flexibility and interaction with inflexible structures is presented. While there are distinct themes, many overlap across the sections of this chapter, which contributes to the holistic perspective offered throughout this thesis. This chapter will provide a description of the experience of fibromyalgia in the SA context, which will contribute to furthering knowledge on the subject.

Diagnosis

In discussing illness experience, it is important to acknowledge the role of diagnosis, prognosis, treatment, social support and institutions in shaping the appearance and outcomes of that experience. In this chapter, diagnosis will be discussed with a particular focus on the complexity presented by fibromyalgia as a contested condition. It will be shown how symptom recognition, events, peers, health beliefs and knowledge, health care access and practitioner interaction all contribute towards the production of a specific process of diagnosing fibromyalgia in SA. This is will be done by using the experiences described by the participants involved in the study undertaken here. There is a connection or 'commonality' between the findings presented here, and arguments made later in this thesis. This appears especially in relation to the continuing themes of **legitimacy and credibility; social support; flexibility and bureaucracy; and prognosis and unpredictability.**

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This chapter will focus on the forms and functions of diagnosis, and the role it plays in transforming a person into a patient by bringing them into contact with healthcare practitioners, medical services, and various treatment options (Timmermans, 2013). The central organising features of diagnosis are critical to understand when viewing conditions such as fibromyalgia, as the processes that follow the diagnosis of a condition are only partially completed within the illness experience of fibromyalgia. The expectation, when seeking a diagnosis and medical assistance, is that the health crisis will be resolved. This is characterised by Frank (1997) as the "restitution" narrative.

The hope is that following diagnosis, the patient will be able to move through and out of the 'sick role', and receive treatments that alleviate symptoms and facilitate the restoration of health. What occurs more frequently in the experience of contested, elusive conditions (like fibromyalgia) is that entry into the 'sick role' through diagnosis and medical consultation is complicated by the vague aetiology of the condition, and the range and ineffectiveness of treatments attached to the diagnosis. This typically results in "chaos" narratives, where illness

is exacerbated by the inability of biomedicine to diagnose accurately, predict prognosis, or offer alleviating treatments (Frank, 1997).

The hierarchy of biomedical diagnosis, the position of fibromyalgia within the hierarchy, as well as the consequences of adopting what can be a vague and insecure diagnosis, are explored within this chapter. While participants in this study utilised both biomedical and complementary and alternative health services, all diagnoses discussed by those interviewed were received in a biomedical healthcare setting. Many of the challenges faced within the diagnosis of fibromyalgia and its treatment relates to the following realities:

- pain more generally is poorly understood within biomedical practice;
- much of the experience, and many of the symptoms, are invisible;
- the processes, knowledge, techniques and technologies used in diagnosing these conditions are unevenly distributed across various contexts (such as those disparities seen between medical discourse and practice) and;
- All these factors were specifically displayed in this study conducted in SA.

First, a discussion of the broad categorisation and labelling of disease and illness will be undertaken. This occurs before explaining the functions of diagnosis within individual, medical and social experience. This is then linked to the specific case study of fibromyalgia in SA, a country where very little is known about contested chronic illnesses. A description of fibromyalgia, including the contested and various understandings of the label, will follow. Closing off this section is the discussion of the manner in which the diagnosis of fibromyalgia explains the inexplicable, and offers a partial and often insufficient account of the experience of the illness. Included in this is a discussion of the associated expectations and treatments, and opportunities and limitations found in adopting the diagnosis.

Symptoms, recognition that "something is wrong" and articulation as fibromyalgia

Werner et al (2003) usefully describe the notion of a "recognising attitude", which enables patients and practitioners to frame their experiences and interactions. This means that terms

are used which appeal across the divide that separates the people feeling the symptoms from those who assist and care for them. The recognizing attitude discussed by Werner et al (2003) is similar to Slim et al (2011) discussion of musculoskeletal pain incidence in Lebanon. Slim et al (2011) emphasise the need for awareness of the condition, availability of practitioners to diagnose, and recognition of symptoms as requiring attention and intervention. As so many of the symptoms found in chronic pain, the musculoskeletal varieties, and fibromyalgia specifically, appear in ordinary existence to lesser degrees, the capacity to see what is happening as illness requires:

- a recognizing attitude from the person going through the experience;
- the family, peers and support network surrounding them;
- the health care services and providers they can access;
- In addition, the cultural understandings of pain and exhaustion that circulate in their social environment.

An alignment of all these factors is what leads to an individual seeking out an explanation for their exceptional and often overwhelming symptoms. Furthermore, having realised that something is amiss, finding a practitioner that will recognise the symptoms as characteristic of fibromyalgia is not a given. It requires persistence and insistence on the part of the patient to discover a clinical account of their experience (Cunningham and Jillings, 2006). This was illustrated in Chloe's story of getting her diagnosis, where she had to see practitioners for a year before she arrived at the label of fibromyalgia.

Since fibromyalgia appears alongside and among various conditions, attaining the specific diagnosis is not straightforward, and many participants in my study spoke in their interviews of their frustration resulting from unsatisfactory medical consultations. The findings of this study show that diagnosing fibromyalgia presents particular challenges, first in accessing the diagnosis, and then categorising the symptoms under that label. There are also difficulties faced after diagnosis, where a quest ensues to adapt and find relief from the symptoms, a stage that is rarely resolved in the doctor's rooms or during the primary consultation (Nettleton et al, 2004). This can be due to the multiplicity of conditions that appear with fibromyalgia, which require repeated interactions with practitioners. Additionally, it could be because either the treatments initially offered do not provide relief, or simply nothing beyond a name or basic description of the condition is offered by the diagnosing doctor.

The narratives collected in the interviews revealed that there are also distinctive stages of worsening symptoms that trigger the search for a better explanation, which precedes the entrance of fibromyalgia as the framework for understanding the illness experience. As was the case for the people in Mendelson's (2009: 398) study on lupus experience, the prompt to seek diagnosis came "only after the symptoms progressed, were amplified, or repeatedly reoccurred". Many of the participants in this study had lived with chronic pain and reoccurring, but intermittent, illness for a long period before being diagnosed with fibromyalgia. Additionally, a number of them explored in their narratives the lack of permanency of their symptoms, and the fact that this often caused them to question their diagnosis, seek out new explanations, or move on from fibromyalgia as an illness identity.

This could be due to the receding severity of fibromyalgia symptoms as they learned to cope with the condition, or when other illnesses became more overwhelming and pressing. Frances, a 59 year old part-time veterinary nurse living in Kwa-Zulu Natal, captured this notion well in explaining that "from my point of view it's not… classic fibromyalgia anymore. And I don't have… not that I've tested tender points for a long time but… I don't think I've got the… it's certainly not what it used to be". She was diagnosed in 1994; by a rheumatologist she had been referred to while seeking treatment for on-going back problems. At that point in time, she was offered anti-depressants and told there was nothing else they could find wrong with her, which would imply the problem was psychological in nature.

Åsbring and Närvänen (2002) explain that this is a common result of medical encounters, where external, visible signs of illness are not found, and the problem is recast as mental sickness. Part of the issue with distinguishing fibromyalgia from mental illness, and the attached stigma experienced with both conditions, is that there are often psychological comorbidities found with patients who experience chronic unexplained pain (Dindo et al, 2012; Alok et al, 2010; Maletic and Raison, 2009; Govender et al, 2011; Escudero-Carretero et al, 2010; Cohen et al, 2011). Furthermore, many of the medications prescribed for the treatment of fibromyalgia are also used in treating depression and anxiety.

Frances said "the rheumatologist came along and did a million and one tests and I can remember him walking in and saying 'don't let anyone tell you that it's in your mind'… because I had an inflammation level which was screamingly high". This reflects Jutel (2010) and Greco's (2012) assertions that many diagnoses which lack biomedical clarity are recast as psychological conditions, when physiological causes cannot be located by practitioners in medical settings. As a result of the stigma attached to mental illness, there is a well-documented tendency to distance oneself as a patient from a psychological diagnosis, and attempt to constantly reassert the physiological experience and reality of fibromyalgia and other MUS (Jackson, 2005; Lillrank, 2003; Lonardi, 2007; Whitehead, 2006; Werner & Malterud, 2003).

These stigmatising processes were evident in the narratives of these study participants, and an analysis of their experiences is explored later. It appears that practitioners are perceived to be dismissive of patients' complaints that are not objectively visible, resulting either from a deliberate shift of responsibility, or from deficient ability (Åsbring and Närvänen 2002; Werner et al, 2004; Mik-Meyer and Obling, 2012). Patients are both directly or implicitly told that their symptoms are imagined, because their 'truth' cannot be easily discovered and explained through biomedical tests and indicators (Cohen et al, 2011). The categorisation of physical symptoms as mental illness is further explained as a theme throughout this thesis, in the analysis of patient-practitioner encounters, and the consequences that appear when explanation for symptoms and treatments and remedies offered are perceived to be insufficient.

There were two clear routes that participants in this study followed having received their diagnosis: either they cemented a relationship with their practitioner and continued consultation and help-seeking with them; or they left their doctor's rooms with the label of fibromyalgia and carried on a quest for acceptance, explanation and relief elsewhere. This is reflected in Zainab's contemplations, when she received the diagnosis of fibromyalgia, and began the process of deciding what it was that she had,

> Is it… because I was quite open to even… because initially I really, like I say, I thought something… terrible wrong with me. But you know, when the doctors says, no nothing, it's

> just pain, this and that… it took me a long time to realise that there wasn't something seriously wrong with me… and… after going to several doctor, doctor, doctor, but I think where it helped is initially… I sort of accepted that maybe this is… psychological… I was open to it, that's… you know… And I decided well, you know, it's up to me, no-one else can do anything but me. And if it's a psychological thing then it's a matter of me deciding how to… live with it or how to manage it or whatever

Inevitably, those who searched further for answers also had greater distrust and difficulty with practitioners than those who found comfort and treatment options that they could adapt around with their healthcare providers (Gilson, 2003).

For Frances, the fact that she had the measurable symptom of inflammation allowed her practitioner to anchor her experience in physiological terms, and turned it into a reality, albeit an unclear one. The insistence that she not let her symptoms be explained away as a psychological issue, despite receiving anti-depressants as a treatment, shows the overall discontinuity caused by attempting to explain fibromyalgia and MUS in a purely biomedical approach. The limitation appears where Cartesian dualism in the biomedical approach denies the link between psychosomatic and physiological factors as causes and outcomes of illness (Arber, 2004). By attempting to reduce and separate out the environmental, psychological and physiological aspects of illness, and treating them in their component parts, biomedicine is unable to comprehend and address conditions like fibromyalgia (Clarke et al, 2007). This occurs because these conditions are multi-faceted, have many manifestations, and require holistic approaches (Meyer, 2006).

To Frances fibromyalgia as a diagnosis was

> A covering letter, so to speak, for… chronic pain. But… and of course, the fact that there are no diagnostic tests and it covers that… um… but there's always that niggling feeling in the back of your mind, well, you know, is there an actual cause for it or is this just an umbrella… diagnosis… you know, kind of, keep you quiet and shut you up so you can tell people that's what's wrong with you. And… ja… it is a difficult thing. I mean, obviously there are conditions that cannot be categorised very easily and they tend to be slotted into… which is frustrating when you feel that, yes there is something wrong and you feel that you've been palmed off with a name. And… I mean having been in medical [or] veterinary type

> environment all my life… its really nice to have a blood test that says… this is what it is… vague things don't sit well with one.

Frances' case demonstrates the applicability of the label as an encompassing name for a range of symptoms that relate to chronic pain. In using the terminology and framework frequently drawn upon in the literature of fibromyalgia, she acknowledges the utility and frustration contained in the diagnosis. She feels she is dismissed and silenced in adopting it, but it still explains and gives meaning to much of what she experiences on a day-to-day basis. It also gives her a definitive treatment options to follow, despite the experimental, adaptive nature of these remedies.

In feeling "palmed off", Frances is expressing her dissatisfaction for a diagnosis that does not give a satisfactory answer for her, in that it is vague and lacks biomedical recognition. This relates to her background and beliefs about health and illness. Her nursing training means she hankers after a biomedical test to prove the existence of the condition, to give it legitimacy for her and those she interacts with (Gardner et al, 2011). She notes how the lack of concrete, visible indicators undermines credibility. Despite acknowledging the existence of conditions that are not easily categorised, for Frances the desire for pinpointed, objective explanations for her illnesses remains (Richardson et al, 2006a; Råheim & Håland, 2006). Additional complexity emerges in her narrative with her shifting state of health.

Having had a series of back operations, and a hysterectomy to treat severe endometriosis, Frances considered many of her fibromyalgia symptoms to have subsided, and her experience with the condition to have been resolved. This led her to feel she could no longer confidently say she had fibromyalgia, and certainly not to the same degree as she had previously experienced. However, this did not exclude pain and exhaustion from her current health schema. The nature and locations of the pain had shifted significantly, from a vague, generalised overwhelming sense of illness related to fibromyalgia, to site-specific "mechanical failure" due to the deterioration of her spine. Frances' telling of her experience displays the utility in using narrative inquiry to investigate complex, contested conditions like fibromyalgia, as the multiplicity of manifestation and non-linear trajectories of the illness can be effectively captured (Sools, 2013; Timmermans, 2013).

The common symptoms of fibromyalgia are explained in greater detail below, but briefly they include "aches, pain, stiffness and feebleness in the muscles, fatigue, headache, swelling, bowel problems, and sleeping difficulties" (Åsbring and Närvänen, 2003: 712). Participants in my study predominantly described overwhelming pain and enduring fatigue, as well as an inability to recover from illness as quickly as they would normally expect. Participants linked their experiences to events, and *diagnosis* represented a fundamental shift in the direction of their illness (Frank, 2010). Importantly, most of the participants had spoken to family and peers, as well as their practitioners about their symptoms, and attempts to make sense of their experience were explored in these spaces. While these interactions constitute a chapter of this thesis on their own, the presence of a recognizing attitude among family and friends was a critical resource for my participants in transforming their symptoms into an illness, and enabling access to diagnosis and treatment.

Michelle, a 51-year-old woman from Johannesburg who also worked in the Netherlands, explained that she had been diagnosed in 1984 with "brain attacks", or a severe form of migraines that are physically disabling. Having undergone treatment for them, she had largely recovered. However, while under the care of a neurologist in 2004, she became convinced that her neurological problems were related to her menstrual cycle, and that the treatment she was receiving was not effective enough. In seeking a clearer answer, she consulted with an endocrinologist in 2006, who immediately told Michelle that,

> "You've got fibro". And she said "and you've got the..." I think if I remember correctly there were 18 pressure points and she checked all of them and she said that I had responded positively or whatever you call it to all 18 points. And I remember her saying she's going to check spots around my legs and I said, "I promise you, you can press as hard as you like on my legs, I don't have pain in my legs". And she got to some little spot and pressed there and it was… so she… and she did a whole lot of blood tests at that time and what was very interesting for me was she… she then told me a whole lot of conditions I had without having even asked me. She said "well you've probably got irritable bowel syndrome, you've probably got migraines, headaches"

Michelle was additionally informed she had hyper-mobility, and that all her symptoms and conditions were linked. Here, her narrative reflects the standardised processes of diagnosing fibromyalgia (Kalla, 2011; Littlejohn and Walker, 2002). She was told that there was a strong correlation between the hyper-mobility and her fibromyalgia (Nijs and Van Houdenhove, 2009). Michelle however, does not accept or identify herself as someone with fibromyalgia in that she associates the diagnosis as being similar to ME (myalgic encephalomyelitis), a condition she does not view as legitimate and valid. Furthermore, because of her previous state of near disability, with her migraines and brain attacks, she was placed on sick leave by her employers in the Netherlands.

In attempting to get back into work, she disclosed the fibromyalgia diagnosis to her doctor in the Netherlands, and experienced disconfirmation and delegitimation of her symptoms (Richardson, 2005). Michelle said in her interview that,

> Um… when I mentioned, in the Netherlands, when I've gone through periods where again… not… clear if it's related to the fibro or to my… to the neurological problem and the medication I was on, but there were periods of time where I was so exhausted I could hardly do anything. I would hardly be able to even get out of bed. Uh and there have been some periods of my life where I couldn't even get out of bed before 11 o'clock in the morning. And um… when I mentioned this to the company doctor she… responded… I said, "oh, my doctor in South Africa says I've got fibromyalgia" and she said, "I beg your pardon?"… I said "fibromyalgia" and she said, "and now Michelle, I'm very worried about you". Because she said "when people start talking about fibromyalgia, I start thinking that they've got a hypochondriac problem. There is no such thing as fibromyalgia. We don't believe it. We believe this is psychological problems of people and if you think that you've got fibromyalgia maybe you need to go for some therapy or… you maybe need to think about what's going on in your life and why you're unhappy and so on… but we don't believe in it here. And it is not an excuse to get out of work". And here I was fighting to try and… get back into work.

This is an excellent example of the necessity of a recognizing attitude, both for the person living with fibromyalgia, and from the practitioners and support structures they interact with (Werner et al, 2003). She also shows the confusion around the causation of her symptoms, as she cannot discern whether it is her neurological condition or her fibromyalgia that creates

exhaustion for her. The overlapping nature of symptoms, and the conditions that spark them, is a characteristic feature of contested chronic conditions, such as fibromyalgia, and leads to a chaotic illness experience, as seen in Michelle's narrative (Nettleton et al, 2004; Meyer, 2006).

The disbelief from Michelle's company doctor in the Netherlands led to scepticism in Michelle's account of her experience, despite being aware and having had experience of the symptoms associated with fibromyalgia. She described in her interview how,

> I don't think of myself as a person with fibro. I don't think of myself as having any illness or anything like that. But I do have times where I think I have what I would call a fibro type flare-up where I really have pain all the way down my neck and into my shoulders, where my joints ache, where my muscles feel sore…

Furthermore, Michelle stated she had received the diagnosis of fibromyalgia from her endocrinologist and her GP in SA; however, she remained unconvinced, and thought it "didn't seem like a very real thing".

In the passages above, there is a clear sense of wanting to know more; both at the point of consulting with the endocrinologist and the GP, as well as the reading Michelle did about fibromyalgia after having received the diagnosis (van Uden-Kraan, 2009). The effect that the disconfirmation from her company doctor had on Michelle's perception of her diagnosis is that she, as a fibromyalgia patient, is discredited (Richardson, 2005). Her ability to call on that diagnosis and the associated positive benefits, such as access to care and treatment, the 'sick role', acceptance and support, are all lost in the face of disbelief (Aujoulat et al, 2007). The fact that Michelle's experience can be so easily discredited is due to the status of fibromyalgia in the medical hierarchy of diagnosis.

As discussed in the literature review, the diagnosis and the currency it holds in medical discourse, where convincing elements, like clear biomedical indicators to make the condition objectively visible, are simply absent (Jutel, 2010). This is in turns contributes to Michelle's sense of doubt about herself as a person with fibromyalgia, even though she continues to

identify the nature of her symptoms within the label and description of fibromyalgia. Another contributing element to the insecurity of her diagnosis, and inability to fully accept it, is that she experiences relative overall wellness, with her "flare-ups" occurring sporadically and with nowhere near the intensity that she was experiencing with her "head attacks". On the spectrum of severity, Michelle's case is mild, in that she has high functionality and has largely adapted her life to accommodate the appearance of symptoms (Audulv et al, 2012). This also contributes to her feelings of uncertainty that fibromyalgia is real; because her experience is not "extraordinary" in the context of the illnesses and disabling symptoms she had previously overcome (Richardson, 2005).

Fibromyalgia and diagnosis sit in contestation with one another, as the former presents complexity and the latter essentially is an organising mechanism, which seeks to clarify and pin-point what the illness is, and why it's being experienced, in order to treat it appropriately. Fibromyalgia is an elusive condition that is difficult to diagnose and concretely explain. One cause of this elusiveness is that fibromyalgia presents among a host of other symptoms and conditions. As such, narrowing down and specifically diagnosing the pain and exhaustion being reported in the consultation with health-care practitioners as fibromyalgia is an arduous process. In an interview conducted for this study, Meyer (2012) usefully drew on the analogy of hypertension for the central nervous system to describe the way fibromyalgia affects pain stimulation and response. In the same way that people with hypertension experience abnormal blood pressure levels, so too do people with fibromyalgia experience elevated sensations of pain. This occurs even in the absence of visible symptoms and stimuli.

It becomes immensely difficult for the patient to articulate and separate what is usually a multitude of symptoms into different experiences and conditions, each of which come with their own names, expectations, outcomes and treatments. As Cunningham and Jillings (2006: 267-268) note in their study of fibromyalgia experience, there are many difficulties that result from a "constellation of interacting factors... [and their participants] continued to encounter skepticism and lack of support from friends, colleagues, and health professionals, due to the invisibility of FM and its questionable legitimacy in the minds of some health care providers". The findings of my study confirm Cunningham and Jillings (2006) assessment of

fibromyalgia as a challenging illness experience, in part, due to the complexity, multiplicity, uncertainty and contestation that surrounds the condition.

Fibromyalgia

Pain can be viewed as a part of everyday life, medically, physiologically, culturally and socially. In converting the meaning of pain from everyday experience to the specific instance of illness, the individual interacts with a number of processes, practitioners and institutions. They are informed, in their interpretation of pain symptoms, by their cultural background, help-seeking behaviour and knowledge, and the advice and treatments available from doctors and other healthcare providers. Especially in the case of SA, access to and availability of medical services also contribute to this process.

As with many illnesses, the presentation and severity of symptoms indicate imbalance within the body, and requires the individual to respond (Blaxter, 2004). The suspension of normality, and the adoption of a medical diagnosis to explain what is happening within the person's body and life, is partially an attempt to make sense of the ongoing experience. Additionally diagnosis is used as a means to overcome the symptoms through recommended treatments and medications. For people with fibromyalgia, in particular, the process is fraught with complication at the points of experiencing diverse and infrequent symptoms, and vague knowledge around the diagnosis when it appears. Belief from practitioners, family, peers, colleagues and employers, as well as experimental treatments and often insufficient medical aid coverage also render the experience of fibromyalgia challenging.

Recognising attitudes and encountering "fibromyalgia"

For many people who participated in this study, pain and exhaustion had been commonplace in their existence, often for years before they had come to their diagnosis of fibromyalgia. The state of health they had experienced previously followed two distinct streams. Either illness onset was sudden; having been "fine" and capable of managing much stress and "busyness" and activity, they quite unexpectedly found new limits on what they could cope

with. Exhaustion became a feature of their experience that could not be dispelled, and they found they had depleted energy that was not restored, even by long periods of rest (Rosenzweig and Thomas, 2009). Another set of participants spoke about their predisposition to illness, as they were often sick when they were growing up, and their experience of fibromyalgia became a continuation of that (Meyer, 2012). Other participants could relate the arrival and exacerbation of their fibromyalgia symptoms to particular events, which often encompassed experience of other illnesses (Arnold, 2010).

Linking the onset of their illness to a set of sequenced events and memories is reflective of the narrative structure through which people tell their experiences (Lupton, 2003). For Chloe, it was a combination of a memorable event, her personality, and predisposition that led to her encountering fibromyalgia. She explained that,

> Well, I think that all my life I've been seen as either a procrastinator or… like I was often missing from school because I was sick, or I had headaches and I've just always been a very tired person… but I thought that was just natural, I thought that was just me. And then I started going to gym with my mom in... 2007. So I think that was first year university… and… I noticed that on the one hand I felt really invigorated after exercising but it would take me an inordinate amount of time to recover and I would have pain, not just where I had been exercising, those joints, but it would spread everywhere. And I was ridiculously tired not just one day after, but for days after exercising. And… I thought that something's not right here. You know me, I've always been not particularly sporty and so I didn't have much of a chance to discover this beforehand… And it just didn't go away when I stopped gymming eventually. And I would notice that if I got a headache then my shoulders would start to hurt and my elbows and my one ankle was just a complete and utter disaster for no known reason… and my hands would get ridiculously cramped, even if I wasn't using them and so we thought something like… osteoporosis or… arthritis but we were like, ag, I was 18 at the time, I think, so it seemed ridiculous but we thought, no, let's go see what's up.

Although Chloe knew that her symptoms were not normal, because of her previous experiences of illness, recognising that there was something legitimately wrong and needed addressing, became an arduous task (Blaxter, 2004). When Chloe's symptoms endured, it indicated that there was clearly a problem. Having stopped going to gym, and while

beginning to see the pattern of the trajectory of her symptoms, she decided to seek help from medical practitioners. She reported that she spent a year going to different doctors, a scenario not unfamiliar to those who experience chronic illness and medically unexplained symptoms (Nettleton et al, 2004; Price and Walker, 2013). Chloe found a practitioner who offered the diagnosis of fibromyalgia after an extensive testing process. However, the practitioner was unable to give relieving treatment, which in turn meant Chloe moved on to find help elsewhere (Mik-Meyer and Obling, 2012). For Chloe, the diagnosis of fibromyalgia enabled her to seek out further explanation and understanding of her symptoms, but the knowledge received from her practitioner was, in her view, "a launch pad".

She wanted to know what her symptoms meant, what embodying the condition entailed but, at a very basic level, she also was after treatments that could lessen the severity and frequency of her symptoms, and move them from the overwhelming to the manageable. Whitehead (2006: 2236), citing Brown (1995), states that diagnosis "is integral to an individual's interpretation and management of an illness, to the theory and practice of medicine, and to social understandings of illness". For the participants in this study, diagnosis proved to be a turning point in their illness career, as symptoms took on new meanings, and interpretations of experiences were shaped fundamentally by the explanatory framework provided by the dispensed label (Aronowitz, 2008; Lillrank, 2003).

Vague diagnoses that have unclear prognoses and lack treatment recommendations that work, also allow for uncertainty and delegitimation to increase as discussed by Sim and Madden (2008). Helena, a 49-year-old woman from Johannesburg, described the impact that getting a diagnosis had in transforming her illness experience. She explained that,

> I must tell you though that prior to diagnosis, and the three years it took them, were really the worst years. It was very difficult after that, but I'm at a point now where I like to think I've got at least 70 percent of my health back. I will for a long time, until they find something to cure this condition with, I will always live with limitations, so it has obviously required an enormous change of lifestyle.

As displayed in Helena's above narrative, and through the experiences of other participants in this study, the lack of clarity in fibromyalgia as a label additionally undermines the potency

of the diagnosis to explain and provide relief for patients. Helena, having regained most of her health, notes the continuous, chronic nature of her fibromyalgia and the fact that, while she has overcome the worst of the symptoms, managing the condition is an ongoing preoccupation.

Framing experience through events appeared as an important feature of the narratives that emerged in this study (Frank, 2010; Keikelame and Swartz, 2013). While participants did not speak about their illnesses and conditions chronologically, they characterised what they had gone through as being linked to particular sequences, memories and events. In recalling what had led to their encounters with fibromyalgia, they drew on a range of memories that detailed their daily lives, and amplified the way in which the condition is intractable from ordinary existence. In speaking about significant events, such as injuries, stressful work situations, marital breakdowns and altered family lives, the participants showed how fibromyalgia was embedded within the pictures that they used to describe their experiences (Råheim and Håland, 2006).

This is a component of story-telling, where a narrative emerges in the milieu of talking about the everyday, and while it is anchored by specific memories, incidents and experiences, it also transcends the detail and sheds light on a "big story" as discussed by Sools (2013). As is the case in this study, often in chronic illness, there is opportunity to reflect on what has happened in a life in a new light, relating things as significant where they might otherwise appear mundane. According to Bury (1982) and Aggleton (1990), interactions, experiences and events are imbued with new meanings as the individual attempts to make sense of the "chaos and confusion" that accompanies ongoing, chronic illness. However, this is not dissimilar to the ways people talk about their life generally, as people speak through memories, placing events sequentially and as causally related.

One crucial strand of narrative that emerged in the course of this study was the manner in which fibromyalgia became a part of the participants' lives. Having moved past a restitution narrative, where hope for resolution of the condition was lost, and into a chaos narrative as relief and meaning for the symptoms was sought, participants were able to draw on a quest

narrative once symptoms had subsided and become manageable (Lupton, 2003, Whitehead, 2006). For one set of the participants, illness had been a part of their story for a long time, where they characterised themselves as having "predisposing" conditions which led to, or came alongside, their experience with fibromyalgia. The predisposition stemmed from factors ranging from other illnesses, to injuries, to life events that triggered the onset of their symptoms that were later diagnosed as constitutive of fibromyalgia (Meyer, 2006).

Claire was a 37-year-old mother of two, who worked as a clinical psychologist, and lived in Johannesburg. While tracing the duration of her symptoms back to her early twenties, she noted a number of factors that contributed towards her experience of unbearable fatigue and pain. For her, pain in the form of headaches had been normalised and had been routinely treated (Lonardi, 2007). However, she recognised her fatigue as abnormal, worsening and at odds with her previous knowledge of herself and her capacities as an active, athletic person, despite her chronic headaches and sinusitis. She thus decided to seek consultation with healthcare practitioners to discover what the new severity of her symptoms meant. She also characterised her condition within the experience of sinusitis and migraines, which are both predisposing features of fibromyalgia and fit within the "Central System Sensitivity" (CSS) explanation of the condition (Rosenzweig and Thomas, 2009; Yunus, 2007). CSS and fibromyalgia are explained in more detail elsewhere in this thesis.

Claire reflected, that

> [In] hindsight, if I look back on the whole process from… probably my… probably about 20, 21, I used to have bouts of fatigue. I used to do a lot of outdoor stuff, I used to climb a lot… the GP was convinced that it was some tick-borne virus that I picked up in somewhere… but it would just be these discrete bouts of like extreme fatigue where 2/3 days I would just be out… um… then towards my mid-20s I would… I've always been a headache sufferer, historically we always put that down to sinusitis… there definitely were sinus problems and I'm not sure at what point there was a cross over between thinking about the headaches as sinusitis and then onto tension headaches. So if I look back at it I started going for physio probably around about 24, 25, 26. [**SC interjection:** For the headaches?]… On a regular basis for headache treatment.

For other participants in the study, fibromyalgia and the associated symptoms and challenges of the condition appeared very definitively after particular events that could be related back to the onset of experiencing episodes of increased pain and exhaustion. Having said this, regardless of whether they had experienced illness for a long time, or it followed certain memorable occasions; all participants reported a steady and explicit worsening of their state of health, where the symptoms of fatigue and pain were overwhelming, enduring and unmanageable.

When initial consultations with practitioners and biomedicine had failed to explain or alleviate the symptoms, they typically spoke to family and peers. Additionally, they consulted the internet and other media sources to gain an understanding of what was happening to them (Conrad and Stults, 2010). Many spoke of the challenges found in getting answers, help from doctors, or finding relief from treatments. This process could be described as what Frank (1997) terms a "restitution" narrative. In telling the story of their illness, participants explained that more than wanting to know what was happening to them; they also wanted something to mitigate the overwhelming nature of their symptoms.

Either participants had co-morbid or predisposing conditions that were underlying factors in the onset of fibromyalgia, or they had starting noticing the symptoms after particular events. Regardless of this, all spoke of the precipitating process of increasing, overwhelming, new and disruptive symptoms that encouraged them to seek diagnosis and treatment, and subsequently have to adapt and cope with fibromyalgia as a part of their lives. They approached healthcare practitioners with the expectation that they could find assistance in overcoming their illness and restore their health and at this point, they were expressing a characteristic "restitution" narrative as described by Travers and Lawler (2008).

Zainab spoke about the ongoing and developing nature of her condition, in that she had experienced illness throughout her life since childhood, and had versions of fibromyalgia for the last 25 years. In her account, she also usefully highlighted the changes in fibromyalgia labelling, in that she initially was diagnosed with fibrositis in the 1980s, which practitioners

later called fibromyalgia (Meyer, 2006). She differentiated between the form of fibromyalgia she currently had, and those symptoms she had previously experienced. She said that,

> Unlike in the 80s when I used to get this very sharp, excruciating pain… just… never know where it's going to come, but it used to mainly affect my arm and… this… but now its… it's just that very tiring, when you wake up in the morning, it's always been that way. You're just very tired, with the headaches, something and the… so it's pain… all over… and some days it's worse… sometimes you wake up and… it also depends on the type of sleep you had… So if you haven't had a good night's sleep the pain seems to just be worse, you know? At the end of the day it's more like being an old person. [Chuckling].

For Zainab, fibromyalgia was an everyday part of her life; she managed her symptoms and was rigorous in altering her lifestyle, diet and treatments. Having normalised fibromyalgia into her health experience, she noted the importance of accepting the condition, not allowing it to dominate her existence, but being cautious of the situations and strains that worsened her symptoms. This approach to self-management, following Travers and Lawler (2008), is referred to "living within limits", whereby constraints are recognised and deliberately used to avoid overexerting oneself and exacerbating symptoms. It is seen as a protective strategy that follows acceptance of one's capacity and the meaning of fibromyalgia in a person's life, and in turn allows them to optimise the quality of their experiences with the condition. These tactics are discussed further in the analysis of how different people addressed and managed fibromyalgia, under the 'Treatment' chapter in this thesis.

Frances, Shreela and Connie could trace the onset of their symptoms, which eventually resulted in a diagnosis of fibromyalgia, along the path of specific events and consequent illness. Shreela captured the intricacy of fibromyalgia as a condition in her narrative, in that a variety of factors contributed to the onset of her illness, and the difficulty of attaining diagnosis is displayed in her telling of events. Furthermore, the disparate patterning of her symptoms, and the murky links made between triggers and outcomes, are characteristic of MUS and fibromyalgia in particular (Madden and Sim, 2006). Fibromyalgia is a spectrum condition, in that it appears with a range of other illnesses which filter into the symptom severity one experiences.

There are also associated predisposing, precipitating and perpetuating factors that can help indicate the form and degree of fibromyalgia being felt (Meyer, 2012). Shreela had a clear understanding of fibromyalgia, and distinguished herself from other people who had predisposing factors associated with the condition. She explained that,

> I don't have, as far as I know, other conditions that um… extenuate the FMS. And so when I think of myself as a FMS… person… as someone with a FMS condition… I see myself at the early end of the continuum rather than at the… the severe end. So I don't have severe allergies or… um… anything, you know… dysfunctional thyroid, or anything like that. What I do know is that what triggered my… um, condition is… I went to… Angola for a conference in 1998. And before I went to Angola… they injected me with… I don't know… anti- yellow fever, well a yellow fever vaccination, I had a polio vaccination, I had a hepatitis vaccination, all at once. And they put me on anti-malarials. And a week into my stay in Angola, I was ill. And the moment I came home I went into this… you know, where the homeopath called me a walking liver because… I literally couldn't move… The liver… is… I think in both… in homeopathic terms definitely, in Chinese medicine terms… and I think in conventional terms… the place where toxins get processed and cleansed out of your body right? And because I had so many of these vaccinations and was taking malarial pills… my body was so toxic, my liver couldn't cope. And what is interesting is that when one has an abscess on your liver, you have very similar symptoms to what I had when I… you know you can't move, you're so tired, you can't walk, you know… so… the liver is crucial for detoxification and when your body is just… what's the word? Bombarded with all these vaccinations… well my liver couldn't cope. And so that's why the homeopaths called me a walking liver. And um… so that is how I understand what triggered the… the fatigue and the, the, the pain. Because my body was completely out of balance.

Like Chloe and Claire, Shreela described how she went "from doctor to doctor, nobody knew what it is I had. I didn't have a virus, I didn't have a bacteria, they checked my colon", and from one practitioner she received the diagnosis of CFS. Having also consulted with a homeopath, Shreela was put on a detox regime, which seemed to work after a period of ten weeks. Her health, however, did not improve permanently, and over the next few years she infrequently experienced episodes of extreme exhaustion, which would then require her to rest until she had restored enough energy to cope with daily routines and demands.

As with Chloe, when the diagnosis of fibromyalgia was proffered to Shreela, the vague description and recommended treatment failed to give explanation and relief, and so Shreela needed to continue searching for a better interpretation of her symptoms. It was important for both Chloe and Shreela that the diagnosis of fibromyalgia made sense, that it clarified and illuminated their experience in terms that made it medically and socially real (Undeland and Malterud, 2007). Additionally, they expected diagnosis to provide guidance for the routes to follow in terms of treatment, and that treatment would be effective without other iatrogenic effects.

For Chloe and Shreela, the prescribed medication from their diagnosing doctors did not result in improved symptoms, and in both cases actively worsened their state of health. Bishop, Yardley and Lewith (2007) found that particular perceptions that people who access and use CAM tend to hold have consequences for their help-seeking behaviour. This includes the belief that psychological factors play a role in causing illness, and in maintaining health, as well as the fact that "beliefs about the importance of holistic and natural treatments reflect an emphasis on treating the whole person (not just the symptoms) and using natural methods or remedies" (Bishop et al, 2007: 858). This was the case for Shreela, as she understood her condition to be the result of physical, emotional and psychological factors, and that attaining health involved the achievement of balance.

Shreela explained that the doctor who diagnosed her did not know much about fibromyalgia. The doctor labelled it as a syndrome, and told her that there was much uncertainty surrounding the causes of the condition. She stated that,

> The only thing he knew at the time was that… what are they called? Tri-cyclic anti-depressants... um… are… are what FMS patients… are what help FMS patients. So he put me on… I don't remember what it was called but a tri-cyclic something or another. And I was walking around like a zombie on 5 milligrams of this stuff a day for a week and I then just decided, I'm sorry, I… I can't do this.

Chloe had a similar experience, and for both her and Shreela, seeking out a sufficient explanation and relieving treatments became a way of steering through the chaos and confusion they were experiencing alongside overwhelming symptoms of pain and exhaustion.

The participants of Whitehead's (2006: 241) study on ME/CFS "used books, media publicity and complementary/alternative medicine to help interpret their symptoms and then support the diagnostic label". This is a similar process that people in my study undertook, while internalising their diagnosis of fibromyalgia. They consulted with various practitioners and sources of health knowledge, most notably peers, family and partners. Chloe and Shreela, as well as other participants, found that the internet constituted a critical tool for clarifying the meanings of the diagnosis, and the associated expectations of the illness, as well as possibilities for treatments and relief (Powell et al, 2003; Barker, 2010). As discussed in the media content analysis of this thesis, information found online and in news articles relating to fibromyalgia shape general perceptions of the condition. Like the people involved in Price and Walker's (2013) study on lupus, searching for information on the internet became a mechanism through which participants in my study could come to terms with their condition. This was enacted through gaining understanding of the explanations, shared experience, and treatment options detailed on the sites they consulted.

Consulting with these different sources constituted an important stage in the illness career of people living with fibromyalgia. Fibromyalgia appears in such diverse and unpredictable forms. Because responses to the condition are so variable, having a support network of people, and a range knowledge that allows the individual to make sense of their condition, is critical to coping with the illness (Arnold et al, 2008). The role of health knowledge sources was a significant factor at many stages of my participants' illness career with fibromyalgia. For three of the participants, the internet, other media sources, and peers were vital tools in coming to the label of fibromyalgia.

Jenna, who had previously diagnosed with ME, and was forced to work from home and live within strict limitations in order to manage her very severe symptoms, had encountered fibromyalgia first in a book. She then went onto the internet, searching for information and in doing so, she found a trove of knowledge and experience being shared online that she could relate to, absorb, and utilise (Conrad and Stults, 2010). At the point of our interview, Jenna was reluctant to tell her practitioners that she thought she had fibromyalgia. She feared

stigmatisation and found sanctuary in the internet, where she connects with others who were struggling with symptoms similar to hers. Beth had lived with arthritic conditions for many years, having inherited them from her parents, and had had episodes of chronic fatigue too.

In her narrative she spoke about the experiences in interweaved ways, and described how,

> **Beth:** It's a continuum. Ok, So I… my father had ankylosing spondylitis.
>
> **SC:** Ok. Which is what?
>
> **Beth:** Um… it's particularly your spine but also some of your joints. I don't think my father ever had… um other joints. Um… and it's mainly men. I think it's more common in women, you just don't see it. Because classically you're bent over like this and women never lie in bed long enough… to stay like that so they're more… and in its severe form, the reason it's got that funny name, your joints just grow together. So you get somebody with a spine that's… they call it a bamboo spine as the joints have grown into each other. So I developed that when I was 18. I think my father must have developed it after 20. Um. And then I got it in places like shoulders, hips, knees… and some of my fingers. And then… I got what I… think of as ME… in '85. That was my first ME. And I don't know the difference between ME and fibromyalgia.
>
> **SC:** Ok, what was ME for you in 1985?
>
> **Beth:** An absolute classical thing is that tiredness and you look at these steps and you think how am I going to get up these steps? And you could be… it can be 5 steps. So it's incredible weakness here… Upper arms. Like this thing of I just can't hang up the washing. I can't get my arms up there. And… incredible tiredness. The kind of tiredness where getting out of a chair to go and make cup of tea is like a major thing, ja. And I had been overworking and then I went on holiday and it took… it took 6 weeks to… I can't pinpoint when I developed fibromyalgia.

Beth noted the overlap and connections between her various ailments, and had engaged in knowledge-seeking to find out the meanings of her overwhelming exhaustion and pain. After a conversation with a colleague, who had fibromyalgia herself, Beth was exploring the possibility of the features of her symptoms as being classifiable as fibromyalgia. She was in the process of going to a specialist rheumatologist, recommended by her colleague, at the

time of our interview. Claire had also self-diagnosed with fibromyalgia. Having sought the information she needed online, utilised that knowledge to consult with her practitioner who confirmed the diagnosis, and began tailoring her treatments and lifestyle to accommodate the demands of the condition (Conrad and Stults, 2010).

There was consultation all the way along the process, from recognising symptoms, to articulating experience, to attaining diagnosis, and then adapting to the condition and its associated meanings, constraints and demands. While this theme is discussed in more detail later on in this thesis, it is important to note here that families, peers, colleagues, employers and practitioners all shaped the illness experience of fibromyalgia for the participants of my study (Cunningham and Jillings, 2006; Escudero-Carretero et al, 2010).

People with a strong support base fared better than those who were isolated and were navigating through the confusing terrain of fibromyalgia alone (Gage, 2013). The particular impact of a recognising attitude could be seen through the narratives of my participants, in that they could acknowledge their experience as important, real, and in need of attention and care (Werner et al, 2003). Furthermore, where relationships with healthcare providers, family members, partners and peers were strong and encouraging, those living with fibromyalgia felt able to express the challenges they experienced, and could address them accordingly. It meant they could also make the changes required to their lifestyles, in moving into different working arrangements, taking on less strenuous roles in their family and home lives, and being selective with how they socialised (Audulv et al, 2012). When participants felt they constantly needed to insist that their symptoms were significant, and their experience legitimate, they also felt pressure to maintain previous roles in their home and work lives, which could be at odds with their fibromyalgia. This meant that the demands being placed on them were incongruent with their new capacity and limitation brought on by the condition. This theme is explored further in the chapters that discuss "institutional responses" to fibromyalgia, as well as "strategies for success".

The social actors that play significant roles in the individual's illness career include: family members, peers, colleagues, partners, and health care practitioners. All of them are important

sources of health knowledge, in that information, advice, direction and suggestion are shared in the interaction. The individual subsequently follows particular routes based on what they been told. This was brought to the fore in my study, since many of the participants had repeatedly discussed, at length, what they should do, and how they could interpret their symptoms, long before they sought diagnosis for their symptoms. Consistent with Lupton's (2003) assertion about the centrality of narrative for those experiencing sickness, both at the point of experiencing illness, and within the patient-practitioner encounter, in this study narrative was used to elicit subjective, objective, social and medical meaning. It additionally assists with making sense of disruptive and often disabling symptoms.

Connie was a 40-year-old mother of two, and she spoke about the fact that it took her 10 years to get the diagnosis of fibromyalgia. After a series of car accidents in her early 20s, she had lived with chronic pain for 20 years. Having visited a number of practitioners and undergoing multiple treatments, she had come to a practitioner who offered the diagnosis of fibromyalgia, which is when she initially found an improvement in her symptoms (Ablin et al, 2012). Connie and Claire notably talked about the role of constructing narrative prior to entering the practitioner's rooms, as well as the significance of finding a practitioner who could accept their symptoms and diagnose them accordingly.

During the interview, Connie showed the difficulty of living with overwhelming, disabling illness that made her, in Lupton's (2003: 95) terms, a "permanent patient… [where her] definition of self can be severely challenged", and where explanation and relief was constantly sought. Connie showed the frustration of being told there was nothing wrong with her, despite knowing that her symptoms were ongoing and unmanageable. This relates to Werner et al's (2003) discussion of women's experiences of inexplicable pain where Connie's symptoms and the lack of visibility thereof, as well as her position as a woman, meant that an amount of resourcefulness and determination was required in order to pursue and attain the diagnosis (Barker, 2008). Having come to the decision that what she was going through was real, and definitely in need of medical attention, Connie began actively seeking out a practitioner who would believe her and take her illness seriously.

Credibility and de-legitimisation

Like many of the participants in my study, Connie made extensive efforts to "appear credible" as a patient, a practice reflected in the experiences analysed by Werner and Malterud (2003). Werner and Malterud (2003: 1412) explain that, for their participants, the work of being a credible patient was done through multiple consultations with "different doctors and [they] looked for help and information from many alternative sources to identify the cause and treatment of their health conditions". This was the case for the people I spoke to in the course of my study, and is a broad theme discussed further in the 'prognosis and sickness' chapter of this thesis.

In the following passage, Connie usefully describes the influential role that the "experts" around her play in suggesting practitioners for her to see, directing her actions, and assisting her in taking control of her illness and treatment. In seeking credibility, she embodies the role and behaviours of a responsible patient (Mik-Meyer, 2011). She explained that,

> One day I walked into the rooms he [her doctor] told me once again "there's nothing wrong with you" and I told him "but doctor, this is impossible. I can't sleep, I can't turn, I can't get up from the bed. I have difficulty driving. I can't move properly around because it's stuck here you know. And you tell me that there's nothing wrong". He says, "because there's nothing wrong with you". I said to him "fine, then I want a copy of my entire file. All the reports from Dr. Erasmus, all the orthopaedic surgeons I've been through... I want all those reports, all those blood tests, everything that you have done over the years. Everything. I'm going to find me a doctor that knows what's wrong with me". And I managed to find a doctor; I don't remember his name… But I said "I'm going to find myself a doctor that knows what is wrong with me". So I got there and I put the report there but I said to the doctor straight away…. I said to him "please, I'm going to tell you my problem and then you must tell me just straight away, can you help me or can you not help me. Are you that doctor to see me?" Because people keep on telling me you've got all these experts out there, you know you talk to your aunty and then she's an expert in this. Then you talk to your supervisor [at work] and she's another expert. So everyone tells you "maybe you should see a rheumatologist", so now I'm going there… He's a rheumatologist. So I said to him "you know, my problem is this happened. I've gone through a few doctors". And he looked at me, and he said to me "you've

> got what we call fibromyalgia". I said "fibro my what?" He says, "fibromyalgia". That was the first time I heard fibromyalgia.

Clearly evident in her narrative was the challenge the condition presents, in that projecting out a subjective experience was only productive in circumstances where a "recognising attitude" was present. Having experienced contestation and confusion alongside overwhelming symptoms for 10 years, Connie was finally offered a name, a label, and an explanation that contextualised her experience in medical terms. It made her experience acceptable and recognised as a condition, and allowed her to embody the 'sick role' of a fibromyalgia patient (van Hal et al, 2013). While she had experienced illness and worsened symptoms at different points in her illness career since then, receiving the diagnosis of fibromyalgia was, for her and other people in my study, a significant turning point in living with the condition. It was a moment when her pain and exhaustion were transformed in their meaning, and the difficulties faced in attaining diagnosis reflect Carlson's (2000: 220) assertion that the inability to explain women's experiences is connected with the cultural focus on male norms for health and disease. It is also indicative of women's position in practitioner-patient encounters that Claire could not attain credibility for her experience, as it can be a space where doctors and biomedicine do not take complaints from women about their health seriously (Barker, 2005). Claire also went through the process of insistence and disbelief, an experience that led her to turn to other sources of information and counsel, rather than medical practitioners (Barker, 2008). Her narrative highlighted the role of peer group support and self-diagnosis in coming to the label of fibromyalgia as the explanatory mechanism for her symptoms (Gage, 2013).

While this is explored in more depth elsewhere in this thesis, it is relevant here in unpacking the route through which people with fibromyalgia come to a practitioner who can diagnose them appropriately. Having experienced disconfirmation and scepticism from many people in her life, particularly her family and her practitioners, Claire was cautious about discussing her illness, and her perspectives of her symptoms and her experiences. It was through a chance encounter with a peer that led to her discovering the practitioner who eventually officially diagnosed her with fibromyalgia, and offered a tailored treatment regimen designed specifically for the condition. In the description below, Claire also shows the role that social

capital played in her gaining her fibromyalgia diagnosis (Åsbring and Närvänen, 2004). She reflected that,

> It was actually a passing comment where I had said to her daughter… uh… you know, you're struggling and… and I think I've finally worked out what I've got, I think I've got fibro and she "oh ja, my mom's got- been diagnosed with that, you should go see her doctor". And I though, ag, you know, I don't know that anybody can do much more than what I'm doing and… then… she actually got me into contact with him, bullied his receptionist, begged and pleaded with him.

Having previously self-diagnosed with fibromyalgia through reading medical journals and other sources on the internet, Claire first took the label to her GP, who was supportive, if cautious, in engaging with it. Claire discovered the same turning point in her fibromyalgia illness career that other people in my study described, despite having initially self-diagnosed. Finding a GP who accepted her condition, and attempted to treat it, proved a crucial element in shaping her illness experience and outcomes positively, and this held for other people I spoke to in the course of this research process. Claire characterised the action of taking the diagnosis to her GP as follows,

> I think what made it safe for me to take the diagnosis to the doctor was um… the fact that I'd built up quite a solid relationship with him and what I really kind of felt was… a quality of him is that I… it was one of the few doctors that I felt… really would hear me and would really take me seriously… and… I also kind of felt he didn't over-prescribe but he would… if you went and said that I'm in pain… he would think about what he could give you to take that pain away. And I just felt that he was very engaging and it felt… it felt that… ja, he took me seriously, kind of regarded me as a person capable of making my own thoughts and reaching my own conclusions and I think that's what made it safe for me to take the diagnosis to him. I don't think I would have done that with a lot of other doctors.
>
> I tell you, like… working with him… was like slowly getting my life back. In terms of like, not waking up in the morning and being too stiff to walk… um but it was still kind of like… you know, you still kind of want that official diagnosis by like, an expert who says "right, this is what you've got". And I think… I started… I put the pieces together in 2010 and then… towards the end of the year I became confident to start speaking to people and saying "I think this is what I've got". And then… that's when… then got referred onto Prof Meyer.

Prof Meyer was interviewed for this study too. He gave Claire an official diagnosis of fibromyalgia and explained, in concrete terms, the nature of the condition, why she was experiencing it, as well as what treatment could be used to relieve her symptoms. Claire explained that,

> Um… my GP, when I first mentioned it to him… he was kind of bit like, "ok, a lot of people don't believe in this but… you know… there's not a lot of literature on it but let's take it to be real". And he never looked at the causes of it. At that point I was quite convinced that it was more personality driven. I was, I was quite convinced that… I sort of arrogantly grew up with this attitude of I cannot push myself to hard… you know I can just cope with everything. I can manage anything. You can bring it my way. I can do it. I will do it. I always just think… not being a superhero has been life's biggest disappointment. [chuckling]. At that point I just really though it was… it was very personality driven. I grew up being physically very fit. And I just assumed that like… maybe, I literally thought, I've broken my body. Like ok, this is stress related. Too many stress chemicals going around… um I think what helped was speaking to Prof Meyer about it and him saying, well you know, there's a genetic component. Looking at my family history, that there's arthritis on both sides of my family… and… him saying it's not only about stress, it's also… about your body. He… I mean primarily he sort of explained… he works with a pain regime of slow release Tramal, Tramaset if you have breakthrough pain… Lyrica, sleeping tablets… and… because I was also quite hesitant… because a lot… at that stage, my sleep was badly affected.

This is also illustrated in Connie's description of her experience of being diagnosed with fibromyalgia, where a clear explanation of the label was offered, but a treatment route could not be dispensed by her practitioner (Rosenzweig & Thomas, 2009). What he could do, however, was to locate her current illness in the context of her life and medical history, and identify the interplay between her actions and symptom onset. He was also to explain that, for her, particular actions and activities would exacerbate her condition, and how she should avoid them. Connie related that,

> In 2000 I went to see him in Rosebank. He then explained to me that fibro is the muscles and myalgia is something that they don't have a diagnosis for but it's some inflammation in the muscles. He said to me, in just plain Afrikaans, it is chronic muscle spasm. "In other words", he says to me, "the day you were in your car accident from the shock, your nerve points got

> hurt. He says, "most probably not as much in the first car accident, the second one on top of the first one just worsened it because then what happened is the nerve endings burnt out completely". So he says "it is very closely linked to the muscle. So your muscles are like this [fist clenched] all the time. Now you go, on a good day you feel very good. You go work in the garden and you just bend wrong, stretch or whatever, any form of stretching is bad". He says, "then you pull that muscle, inflammation comes in there immediately and what this muscle is saying to you is, ja[9] right, you think you're going to pull me while I'm already like this, I'm going to show you and I will make you pay for the stretch that you've just done here". And then ten minutes later when it becomes cold that's when the inflammation is there. So some days it's hot here in my lower back. I call this my soft spot it's here, this part here, the lower back. My soft spot. No one can touch me there. No one.

In the above exchange, Connie's practitioner usefully tells her why she experiences debilitating pain, what is happening to her, and what specifically triggers the onset of her symptoms. However, the narrative also shows the complexity of a condition like fibromyalgia, in that it is so intricately tied to everyday living, and a bad movement or muscle pull appears unpredictably, making avoiding the action difficult (Morris et al, 2011; May, 2005). As Chloe plainly stated during our interview, a flare-up can occur anytime, as "there is no fixed trigger. Whether you do something right or wrong, it can happen".

Uncertainty, contestation and challenge

Barker (2011: 834) explains that in this context of uncertainty, a contradiction emerges between little biomedical, visible, objective evidence and “significant reductions in functional abilities, health status, and quality of life, with little sustained improvement, in well-being over time” for the patient in their illness experience. Following Conrad & Stults (2008), Barker (2011: 834) places these phenomena under the banner of “contested illnesses”, and notes the increases in reported cases over the last two decades. Barker (2011: 834) uses this term “precisely because they represent a clash between biomedical knowledge and patient experience... [And] sufferers must therefore engage in an ongoing struggle to have medically unexplainable symptoms recognized in orthodox biomedical terms despite resistance from medical professionals and institutions”. Offering a more comprehensive and nuanced

[9] "Ja" is Afrikaans for "yes" and is commonplace in South African speech.

understanding of this conflict, and how contestation was experienced by those living with fibromyalgia, was at the heart of the research question posed in this study.

Meyer (2006) describes "fibrositis syndrome" as emerging in the 1970s and the symptoms of the condition were later relabelled as "fibromyalgia", following the ACR recommendations published in 1990. This is a relatively recent leap in the legitimacy of pain and exhaustion experience of this form. Fibromyalgia, as a diagnosis, means that mechanisms and testing criteria are still evolving and developing, and are distributed unevenly. The manner in which medical knowledge and clinical credibility circulates allows authorities (such as the ACR) to accept and establish a condition as legitimate, and therefore worthy of recognition and resources in the biomedical realm. However, the filtering process of the condition into medical practice, institutions, and society at large may not occur as smoothly.

This opens up gaps between medical discourse, patient experience and institutional and policy response, all while trying to cope with a condition which ranges from mild to disabling in its symptom severity and appears in diverse forms (Dumit, 2006). Zainab, who had experienced pain and exhaustion for last 20 years, first encountered the diagnosis of "fibrositis" which was later relabelled as "fibromyalgia". This is a representation of the processes discussed above, as well as the transitionary nature of diagnosis where clearer explanations become available in line with increased recognition and legitimation of the illness (Barker, 2011; Werner et al, 2003; Cho et al, 2009).

Features of fibromyalgia

Participants in this study describe fibromyalgia in terms of chronic pain and exhaustion, which sit on a continuum with some symptoms being more predominant than others are at different times. Many of them noticed their symptoms being affected or worsened by the onset of other illness conditions, such as flu and colds, headaches or migraines, stress, seasonal change, and spectrum mood disorders. As Barker (2011) described, managing fibromyalgia involves the consideration of multiple symptoms and conditions, and the capacity to capture all of this in diagnosing and treating the patient. All of the participants in this study had experienced a host of other conditions alongside fibromyalgia. These included:

IBS[10], migraines, endometriosis, sinusitis and thyroid complications, which, at different points, appeared more pertinent, and in need of greater attention than their fibromyalgia. Many also spoke of their family histories of chronic illness, including diabetes and various forms of arthritis.

Schachna and Littlejohn (1999: 470) explain that, along with increased incidence of fibromyalgia with daughters of mothers who have the condition, episodes "of persistent pain, such as headache or pelvic pain due to endometriosis, may precede fibromyalgia". This relates to the gendered nature of fibromyalgia insofar as the genetic aspects of the condition connects women of different ages (mothers and daughters), and the symptoms of pain are given recognition through other conditions, like endometriosis, that typically only affect women (Barker, 2005). Fibromyalgia also underscored the worsening experience of illness for many of the participants, and created a sense of living on the back-foot, or consistently playing catch-up in conducting their daily routines. The participants were able to vividly describe the character and form of their pain, and how it could be distinguished from pain caused by other conditions. Chloe, a 23 year old woman from Johannesburg who was diagnosed with fibromyalgia in 2007 explained during the interview that,

> There are all sorts of different types of pain; I get all sorts of flavours. A headache is one thing… but there's nothing to say that's directly linked to fibromyalgia. The most predominant one is just… it's difficult to explain it. Sometimes it feels like it's my flesh itself… or my bones are on fire. And it's not just localised to the joints or anything. It could be… here, it could be here [running hand along her arm, calf and thigh]. In fact it is most often here [holding upper arm]. Just… I can't even think if its flesh or bones or skin, it's just there. So it's often a burny kind of sensation. Very rarely sharp, but it can be. It can be like little spikes of sharp pain. Sometimes it's… um, there's a term for it, pressure related. So if I press on it then it's sore.

The exhaustion too was distinctive in being overwhelming, and sometimes was more difficult to cope with than the pain. For instance, Claire described her exhaustion as follows:

> The symptoms really started to become quite difficult… when I used to go to doctors saying… because at that point I was still physically very active… um, so the pain was still

[10] Irritable Bowel Syndrome

> quite contained, just headaches but when I used to go to doctors and say to them… "like this fatigue is unmanageable… I can't, I can't do the fatigue". And I think the worst thing that you could do to a doctor is walk into their room and say "I'm tired". [Chuckling]. Because they… they first test you for iron… then they might test you for TB and then they tell you that you're depressed and… I would try and argue with them and I would try and say to them… like… I work in the field, I don't think this is depression, this is… I'm just tired. It's not like… I don't have thoughts or I don't have things that I wanna do it's just that I'm… I don't have the energy to do them anymore. And this is going from someone who used to… I mean I used to be… I'd play squash several nights a week, I would swim regularly, I would run… and you know… the fatigue felt just so uncharacteristic and felt so debilitating. Eventually… they always wanted to put me on anti-depressant; I was always like, "no, no, no I'll just cope". And then after the birth of my first child, that's when it really started to hit me.

Here, Claire has spoken about an important aspect of diagnosing fibromyalgia, in that the symptom of exhaustion is ubiquitous across many states of health, and can be an indication that there is nothing to worry about, or that many things could be wrong. For Claire and other participants in this study, telling practitioners that they were "tired" or fatigued served as the first obstacle in attaining diagnosis, and appeared as a tangible source of derision and delegitimation (May, 2005). This occurred during both the consultation, and subsequently when they were attempting to make sense of their illness experience. There is consensus in the literature that fibromyalgia is, in part, a diagnosis of exclusion, and due to this, practitioners and patients embark on a necessary process of eliminating other possible explanations for the illness before arriving at the diagnosis (Barker, 2011; Madden and Sim, 2006).

As major "depression or anxiety disorders occur in 30% of patients with fibromyalgia and are independently associated with increased pain severity in fibromyalgia", it is important to account for the spectrum nature of the condition, and the multiplicity that appears with this illness (Schachna and Littlejohn, 1999: 470). However, this can also present opportunities for misdiagnosis of psychiatric conditions, which in turn limit the possibility of diagnosing fibromyalgia and other MUS, as the person and their illness is recast into psychiatric treatment and turned away from holistic medical care (Jutel, 2010). This study has shown that

while psychological comorbities are associated with fibromyalgia experience, psychiatric diagnosis of the symptoms insufficiently captures the complexity of fibromyalgia as an illness experience.

Practitioners and their patients subsequently get caught in a battle of "reality", as people with the condition feel derision for their experience, and so are increasingly insistent about the physicality of their symptoms, the location of it in the body and not the mind, and that their pain and exhaustion is legitimate and not made up (Bieber et al, 2006). The sudden loss of energy, and inability to restore oneself through rest and sleep, was found in many of the stories participants related in the course of this study. Though it was difficult to identify the causes of the pain and fatigue, all the participants could explain their experience in terms of particular stages of pre-diagnosis, diagnosis, prognosis and attempts to relieve symptoms through treatments.

Additional issues arose during the interviews and in the diaries. Participants discussed the sources of knowledge and of social support they drew on, and the relationships with healthcare providers (practitioners and medical aid schemes- common in the SA context) that had shaped their illness experiences. They also spoke about the strategies and decisions they had undertaken to improve their state of health and manage fibromyalgia in their lives. All of these components are discussed individually in later chapters. It is important to note that fibromyalgia offers a partial explanation for this illness experience, and the adoption of the diagnosis was a weighted experience for almost all the participants.

As Schachna and Littlejohn (1999: 471) elaborate, "the decision to apply the label of 'fibromyalgia' to an individual is of importance. For medical illnesses in general, a diagnostic label is an appropriate entry point into a therapeutic paradigm". There is scepticism surrounding the process of diagnosis, especially in cases of chronic illness (Cunningham and Jillings, 2006; May, 2005; Barker, 2008). There is also continued questioning on the part of the individuals, their health-care providers, and social and work communities that surround the individual. For this reason, adopting the diagnosis of fibromyalgia as the explanation through which the experience could be described and understood was a considered choice. It

was a potent statement of belief and required convincing, both for the patients themselves, and for those they interacted with through the experience of this complex condition.

The participants also experienced fibromyalgia to varying degrees, and over different periods of time. All the participants had had the diagnosis for a minimum of two years, with the earliest diagnosis occurring 20 years ago. Some of the participants could recall experiencing symptoms for a much longer period before diagnosis. However, it was when the symptoms became more severe that they then entered a process of searching for an answer to what was happening, and why they were ill. Their insistence for an adequate explanation was dependent on the immediacy with which their symptoms were taken seriously. Furthermore, the recognising attitude from their families and health-care practitioners, and the ability of treatments to provide relief affected the ability to address the condition. This process is unpacked in detail in later sections, but it is noted here that the heterogeneity of the condition of fibromyalgia is reflected in the diversity of illness experience described by participants in this study.

While some participants were able to immediately incorporate fibromyalgia as the explanation for their illness, others had a tougher time in accepting the condition as real, as sufficient, and as the explanation they would use consistently to describe what they were going through. Both internally and externally, many of the participants experienced direct and indirect challenges to the legitimacy of their experience, and the adequacy of fibromyalgia to offer an understanding and framework for their symptoms. Others still actively had their diagnoses removed by secondary health-care practitioners, which created confusion and uncertainty for an experience that had once been anchored by fibromyalgia.

Explaining the Inexplicable

This section will discuss the findings that demonstrate fluidity of fibromyalgia as a diagnosis, the challenge presented by partial medical explanation, and variant treatment options in confronting a heterogeneous condition. The ways in which fibromyalgia simultaneously illuminates and explains pain experience, while leading to further chaos and confusion in attempting to cope with the manifest symptoms, will be explored through a review of the literature and analysis of the findings of this study.

As indicated in the literature, fibromyalgia as a diagnosis simultaneously captures particular pain and generalised experience of soreness and fatigue. This means that people who feel pain of a certain severity, in specified locations for an approximate duration of time, seek help, enter medical practice, and receive a name for what they are going through. This occurs having had a standardised biomedical tender-point test and other investigative questions administered. Fibromyalgia as a diagnostic name, though, also captures the collective experience of symptoms and spectrum conditions related to central system sensitivity, which is broad as a diagnostic category (Yunus, 2007). Participants in my study captured this complexity by speaking of their specific pain that they labelled as fibromyalgia pain, and this was distinct from headache or stomach pain.

They also described the worsening of overall symptom experience and illness as a result of their fibromyalgia. As a result, fibromyalgia was used to speak generally about their predisposition to ill-health, but also for explaining the invisible and severe pain they frequently experienced. This process could be difficult to articulate, especially because the symptoms were disparate, seemingly random at times and often only explainable through saying it was their fibromyalgia (Cunningham and Jillings, 2006). Participants had trouble with using the diagnosis when they could see the catchall, umbrella notion of "it is everything"; while in fact, they had other ailments that might require greater attention, more urgent care, and which are more resolvable than their fibromyalgia.

Because fibromyalgia could almost disappear into the background of their health schema, many participants questioned the realness of the label, whether it was just a matter of will power in order to overcome it, and whether they had been given the correct diagnosis. During our second interview, Claire related how she frequently questioned the tangibility of fibromyalgia in her life, and whether her symptoms were actually the result of mental weakness rather than physical inability. Despite having effective treatment and legitimate confirmation of her experience through the diagnosis of fibromyalgia, Claire continued to doubt the accuracy of the label. She related this tendency to her early encounters and engagements with family and practitioners, who actively undermined the seriousness of her symptoms and her as an ill person.

This made acceptance of the diagnosis of fibromyalgia difficult for her, and she continually questioned the validity of the label. It happened most especially when she experienced other illnesses (like a head cold), or scepticism from people in her broader social circle, such as her ex-husband and colleagues at work. In turn, she extolled the blame for her state of health on herself, rather than contextualising it in the condition of fibromyalgia. She vividly described that,

> I think it's also like, intellectually I can get it… that it's a chronic condition, I get that I need to manage it… but there's something about like… there's still like internally a doubt about… whether maybe I'm just not trying hard enough [chuckling]. And I mean I can see it in my head and I can see how bizarre it sounds… but… emotionally it's how it feels.

There are times when fibromyalgia is the dominant cause of ill-health, and other times when it fades, and barely impacts on day-to-day lived experience. This makes interpreting and adapting to the condition more difficult, because it is unknown what specifically is triggering the onset of symptoms, what alterations could be made in lifestyle choices, and where support (both medical and social) could be drawn from in order to gain relief and return to wellness. However, on this last point, those that questioned the diagnosis were reluctant to move away from it, because they simply did not have a better explanation than fibromyalgia for their symptoms (Undeland and Malterud, 2007). This shows a critical point of the function of diagnosis, and the way that the label of fibromyalgia explains the inexplicable (Jutel, 2010). While it can be vague and has insecure causation and prognosis, it fits the symptoms experienced, gives meaning to a collection of illnesses that are challenging to address, and allows the individual to pursue further treatment and care in order to cope with the condition.

It seems that the removal of the label of fibromyalgia recasts the individual back into a sea of confusion with no guidance, and no explanation for their pain and unrelenting exhaustion. The explanatory power of fibromyalgia as label and diagnosis is limited by the lack of knowledge about its causes, prognosis, and treatments. Having said this, it is still useful in terms of making real an experience that is medically difficult to view, and gives some meaning and clarity for those grappling with the complexity of this unpredictable condition (Mik-Meyer and Obling, 2012). The ability to articulate and frame the reality of living with chronic pain and exhaustion is opportunistic, and dependant on a range of factors coming together.

These include the capacity of the individual to clearly say that there is a problem, a responsive health-care provider, and the explanation being available to be drawn upon- in this case the diagnosis of fibromyalgia. The experience of this process is detailed in later sections of this thesis. Only a couple of the people I spoke to had come to fibromyalgia as a diagnosis immediately, and many more of them had actively searched for up to 10 years to find an explanation for their symptoms, an experience commonly shared by people with conditions that are medically ill-defined (Nettleton et al, 2004, Råheim and Håland, 2006). Fibromyalgia has, by and large, explained much for the participants in my study, by making the inexplicable understandable. However, the unpredictability associated with causes, prognosis and treatments for fibromyalgia has confounded this initial clarity, and created further complexity in an already chaotic illness experience (Stockl, 2007; Glenton, 2003).

When asked to describe the symptoms that were frequently experienced as fibromyalgia, many of the participants were clear about the character of their ailment. However, they also spoke of the elusiveness associated with separating their pain and exhaustion from the milieu of generally feeling unwell. This was, in part, because the form that fibromyalgia pain took resembled a feeling of flu, heaviness, and a sense of severe and widespread soreness. Occasionally the pain would be located to specific sites on the body, such as the joints, spine, head and limbs. Sometimes the pain would be sharp and stabbing in its intensity, and at other times just there, in the background, worsening overall feelings of wellbeing, and exacerbating other illness conditions such as migraines, bronchitis and IBS. This reflects the characteristics of fibromyalgia as described by Meyer (2012), Staud (2009) and Barker (2011).

A few participants described the sensation as "feeling like an old person", having a lack of energy, and finding pain overwhelming. The pain was muscular in nature, and could be attributed to or delinked from particular activities. All of this contributes to the diverse character, and unpredictable causation and manifestation of the condition. Alison, a 23-year-old student from Johannesburg, was a participant who had developed a productive relationship with her doctor, as he was responsive and helpful in addressing her symptoms. He offered explanations of her condition that made sense to her, and that she was confident and comfortable in utilising when relating her diagnosis.

Alison described what her doctor had told her about fibromyalgia, and said that he was able to conclude that this was the correct diagnosis relatively soon after she sought help. Specifically, she explained that,

> Um he said that it was a condition that isn't something that can be treated with medication. He said that… what it is... is that your body… I can't really remember because it was so long ago, but it's kind of my understanding that… um it's a condition that affects your body that if your sleeping patterns aren't right, your exercise isn't up and your eating… eating plans aren't healthy enough, your body starts to go into like… it becomes very unhealthy and then you actually… he says that, he actually describes it as you feel like an old person… that you… that your body aches and you're tired and you're very grumpy and… it's like… I'm like a 60 year old woman… in like a 23 year old body [chuckle]. You know, so that's what he described it as. He said… um… some of the ways to treat it, because obviously medication would be one way, and I have gone on medication for it… like pain… pain pills and things for inflammation and stuff like that… because a lot of it affects… like when I get… um… like flu, then my body is even worse, because I already have the fibromyalgia, it just enhances the condition so um… so I sometimes go on things like anti-inflammatory… or Celebrex which is a muscle relaxant, things like that… just to… you know… calm it down if it gets bad. Other than that, he said that um… exercising. I found that exercising definitely helps…

In the passage above, it is clear that Alison finds the explanation offered useful, in that she could describe what was happening to her, and knew what could be done to alleviate or cope with the symptoms. Additionally, Alison displays the duality discussed earlier, where her exhaustion is specifically related to her fibromyalgia, and her fibromyalgia worsens other symptoms associated with being ill with flu (Meyer, 2012). This shows that framing the condition and its symptoms in relatable ways becomes a task that people living with fibromyalgia need to adapt to, in order to articulate their experience, make sense of what they are going through, and how to cope with it (Thorne et al, 2004).

Other participants spoke about the vague or absent explanations offered by healthcare practitioners. They also discussed the difficulty faced when the diagnosis failed to sufficiently reassure them, their healthcare providers, or the people they interacted with in their working and social lives. Fibromyalgia was offered as a diagnosis to capture the range of symptoms being experienced, a stage that initially brought relief, but later created confusion as further prognoses and treatments were not offered (Richardson, 2005; Undeland and Malterud, 2007).

Furthermore, for many participants, beyond the label of fibromyalgia, no explanation of what the condition meant, what caused it, and what could be done to effectively cope with it was offered by healthcare practitioners. Rebecca (a 32-year-old swimming instructor from Johannesburg) characterised her pain as follows,

> **Rebecca:** it's a lot of pain and, like, so walking up stairs and anything with an incline is very, very difficult. Also if I walk very, very fast my muscles tend to spasm. And then the wrist, it gets like really sore, like it feels like the wrist is broken, it's like I can't push down and I can't…
>
> **SC:** Do stuff…
>
> **Rebecca:** Ja
>
> **SC:** OK and that stems from the fibromyalgia?
>
> **Rebecca:** It's a combination of everything in… it is a fibromyalgia attack when that is happening. It takes the form of like… it feels like my hand is broken, like even moving gears in the car is sore.
>
> Sometimes it can happen once in every three months… um if I'm sick it like exacerbates, like it really… like especially if I've got bronchitis or something I cannot move. It's like I'm extremely sore and then like everything locks and… I mean I know that I have bronchitis and I when I went back to Boot Camp it's like… I was drained. My muscles were completely sore and drained… I mean even like, I have lower back problems as well but with the fibromyalgia its worse, if that makes sense?

Rebecca had also experienced disconfirmation of her diagnosis while consulting with an endocrinologist for ongoing issues with her thyroid. She explained that she had experienced pain for many years, and it was initially labelled as muscle spasms, and "then the muscle spasms led to [the diagnosis] that I have fibromyalgia. But when I spoke to my endocrinologist, he said, 'fibromyalgia is a diagnosis that doctors give you when they don't know what is wrong'". When asked what was convincing about fibromyalgia as a diagnosis, and why she still utilised the label despite the statement from her current health care practitioner, Rebecca said, "because I'm in pain. And the medication that he's given me is not… it's like; I'm still in pain… I'm still like, you know, my arms still… get sore and my legs still get sore, I mean… if I walk really fast my legs are going to spasm".

Here, fibromyalgia is the best description for her pain, and the absence of a better explanation and treatment from her endocrinologist meant that Rebecca would still utilise the label (Madden and Sim, 2006). Another participant, Teresa, a 25-year-old student living in Pietermaritzburg, explained the difficulty that she had encountered when the unpredictable appearance of her symptoms led to a specialist stating that she did not have fibromyalgia, given that her symptoms were not persistent. Teresa explained that the rheumatologist she initially consulted with stated that,

> Referring to my joints, it was only fibromyalgia. She also said that I had Reynaud's… Um, that's also auto-immune, everything I have is auto-immune, fibromyalgia, eczema, asthma, Reynaud's Syndrome which is nothing serious it's just you know when you're cold and go blue and funny colours… and your hands and feet get cold very quickly… it's basically having really bad blood circulation. So… that… too. Um. It made sense, I think… I'd been going to doctors for 2 years about and the thing is you feel kind of stupid going to doctors for something like that because right now, I'm not in pain, you know? I… but it irritates me that I know that I'll do something, I'll be in pain and I won't know why. So… I think just having that was at least like; you have a reason you know? Whether it's true or not … you know…

Teresa expressed deep frustration with her current quandary that she was left in after being told that because her symptoms appeared infrequently, it was unlikely she actually had fibromyalgia. She spoke about the specialist she consulted with, and the fact that she got the referral at a time when she was in pain, but by the time she was able to consult with the specialist, her pain had passed. She described him as a joint and arthritis specialist, and said that,

> When I went there it was sort of, a week, two weeks later… and my hands were fine, they weren't hurting in the time I was there… when I went to see him they were fine. He said, "There's nothing wrong with your hands" and he said, "they were probably swollen and sore then, but the fact that they're not now shows that you don't have… arthritis or anything like that". And then he said that "you really don't have fibromyalgia because for fibromyalgia you have to have a certain amount of things… which are sore" and he was like pressing places on and asking, "is that sore, is that sore?". [I said] "No…" so he was like, "you don't actually fit the profile for fibromyalgia…" so now, you know, 7 years later they're saying, no you don't have fibromyalgia, you know… or 9 years later, they're saying, you don't have fibromyalgia.

> And then I'm like, "well what is it? Because you can't tell me". And that just, it really… it was… very frustrating because it takes everything that you felt, that you feel, that it illegitimizes any pain that you feel, you know? To say, "oh but you don't have it". And then you're like, well I'm not making it up. It makes you feel like you've just made up all this stuff in your head but you haven't made it up, you've been stiff, you've been sore… and he's like, "you know, fibromyalgia is really something that they… they just say when they don't really know what's wrong with you but you've got stiffness in a certain amount of parts… in certain parts, in certain amount of places in your body". And he's like, "obviously you do have some stiffness and everything but… it's not that".

This effectively captures both the complex nature of fibromyalgia, and its status in the hierarchy of medical diagnosis (Album and Westin, 2008). Her narrative also reflects the tensions between attempts to predict the meanings and frequencies of symptoms, and the importance of confirmation and acceptance of the diagnosis in the interactions patients have with health care practitioners (Dumit, 2006; Barker, 2011, Werner et al, 2003). For Teresa, being told that the diagnosis is one of convenience, which is dispensed when no better explanation can be found, disorientates her understanding of her experiences.

Additionally, having the specialist tell her she does not have fibromyalgia means that her illness identity, and the meanings she has attached to her symptoms, as well her knowledge of her condition, are all thrown into disarray. A diagnosis that had previously anchored and navigated her experience, and illuminated the meaning of her pain, is suddenly cast adrift because she does not sufficiently meet the criteria (Cöster et al, 2008). Furthermore, her practitioner will not accept that her symptoms are linked to the condition she has known she has had for nearly a decade. The practitioner additionally does not offer an explanation for her experience of pain and joint stiffness, beyond acknowledging the existence of it. Therefore, without clarity from him, Teresa reverts back to using the label of fibromyalgia to explain what he finds inexplicable.

This section has discussed the findings that focus on the complexity of fibromyalgia as a diagnosis, the manner in which it casts light and meaning upon symptoms, and

simultaneously extinguishes predictability and expectation in terms of prognosis and treatment. Because fibromyalgia as a diagnosis elucidates broad illness experience and specific symptom manifestation, there is room for the picture to become chaotic. This occurs with the distribution of knowledge between medical discourse and practice, and patient narrative being uneven and confusing for people living with the condition. Fibromyalgia is a useful label to explain pain and exhaustion of a particular form. However, its status in the medical diagnosis hierarchy, and the lack of pattern in diagnosis, prognosis and treatment, means that the credibility of this heterogeneous illness condition is easily eroded.

Prognosis and Sickness

As discussed in the literature review, the concepts of ‘health’, ‘illness’, ‘disease’, and ‘sickness’ are central features of this study. For Blaxter (2004), the individuals’ state of health, their experience, and response to illness are defined in reaction to the environment surrounding them. Blaxter (2004), drawing on Mechanic (1968) describes illness behaviour as the various ways people identify symptoms that are consequently assessed and responded to by the individual in line with their particular social circumstances.

The "Diagnosis" chapter of this thesis detailed the stages of fibromyalgia illness experience that lead to diagnosis and treatment being sought, in subjectively recognising symptoms as problematic, and hoping to overcome them with the assistance of medical practitioner. Fibromyalgia characteristically complicates the generally linear process of resolving illness through interaction with biomedical diagnosis, prognosis and treatment; the subjective experience of which was discussed in the previous chapter. In this section, the interlinked subjective and external processes of developing patterned prognosis for fibromyalgia, which accounts for the interspersed episodes of overwhelming symptom experience in a state of relatively stable health, is explored. Later, the negative effects of applying rigid understandings of the 'sick role' and sickness to fibromyalgia as an illness experience are revealed through the narratives of the participants. The experimental attitude used by my participants in determining how to cope with the illness experience of fibromyalgia, and the movement towards alternative and productive accounts of illness and wellness, form a core theme within this chapter and across the thesis.

As previously discussed, chronic illness is not accommodated in the narrow confines of Parsonian conceptualisations of health and illness, because the expectation of a return to wellness cannot always exist (Blaxter, 2010). The passivity of the patient, and the incomprehension of the myriad of factors, actors, norms, values, beliefs and behaviour, that lead individuals down the path from person to patient, is not accounted for. This means there needs to be inclusion of factors beyond the narrow ideal-type functional-system conception presented in Parsonian understandings of the ‘sick role’ (Blaxter, 2010). This critique was

relevant when analysing the narratives collected through this study. This related to the unpredictability of fibromyalgia, and the flexibility required in addressing the condition, which showed the incompatibility of limited Parsonian explanations of the 'sick role'.

Parsonian perspectives of the 'sick role' also fail to account for instances of normalised illness. This was shown in cases where the conventional route of seeking help from healthcare practitioners, and having leave from work and life, were no longer applicable. This was because the experience of illness was frequent, enduring and not resolved by following that pattern of illness behaviour, as reflected in the experiences of these study participants. Fibromyalgia is a chronic condition, and so the recognition of problematic symptoms becomes less apparent as pain and exhaustion are contextualised through the diagnostic label, and converted into normalised sickness (Jackson, 2005).

This means that people living with the condition expect to regularly experience pain and exhaustion, and alter their illness behaviour accordingly, only seeking help for symptoms that appear "extra-ordinary" and are overwhelming or severe (Richardson, 2005). Additionally, having been unable to find relief through consultation with their healthcare providers, many of the participants had turned to self-care, and had taken responsibility for the management of their condition into their own hands (Audulv et al, 2012). This was done for many reasons, including limited healthcare access (in that seeing doctors was prohibitively costly), feelings of rejection from unhelpful practitioners, and the desire to present themselves as legitimate patients who were not "hypochondriacs" or "catastrophizers" (Werner and Malterud, 2003; Basu et al, 2012). The former term was used by my participants and the latter by Prof Meyer, and in the literature on the subject of fibromyalgia (Morris et al, 2011).

Michelle, who had worked in the Netherlands and in SA, displayed many clear examples in her narrative of the attempts made by her employers to apply a rigid form of the 'sick role' in accommodating her in her experience of "head-attacks", a neurological condition she had lived with for a number of years alongside her fibromyalgia. She explained that,

There were periods of time… and it's difficult to know whether it's as a result of the medication or… or fibromyalgia, but I went through periods of time where I could just hardly work at all. And I hardly… to get up and sit down and actually start a piece of work was extremely difficult… um… I had one of these attacks in… I think it was in 2008 and um, the neurologist booked me off work for 3 months… but then I went to the Netherlands and they basically wouldn't… they would only allow me to work 12 hours a week for about 6 months… Because in the Netherlands they have a very strict thing that if you are… "if you are ill, you're ill" and they don't want you to mix being ill and work. So… although I'd been off work for 3 full months here in South Africa, when I went back they did an assessment and they said "no… you've got to ease back into work very slowly and work is for recreation… it's not for work and you can't do any work that will put you under stress or pressure" and so on… but actually it was extremely difficult for me because I was in the Netherlands mainly for my work and I didn't have a huge social network and to not be allowed… I literally was not allowed in the office more than 12 hours a week. And… when I started going in more often and I was working, I needed the work, you know, it's what gave me my fulfilment… they got very upset with me and I was called in… company doctor… I had to go and see her again and she said "you are not allowed in the office more than 12 hours a week and if you go you are actually breaking the law and it will be reported back to me" and I said, "look, it's extremely depressing for me to just sit in my apartment by myself, not seeing my colleagues, I don't have many friends here or friends outside of work and if I was in South Africa fine, I don't mind… only working 12 hours a month, you know when my sister's there and my friends are there and I can… go and do other things but here… it's like a prison sentence". Anyway, so that took quite a long time to… I had to go and see her every month and I would… the first time I saw her I said "you know I'd like to increase it to more hours" and she only allowed… it went from 12 hours to 18 hours to… and then I said, no really I'm much better, I want to go back… and then she only increased it to 24 hours, ja. And I wasn't allowed to, 'cause we have time sheets and I wasn't allowed to record anything more than those specific hours on the time sheets. I think the approach does help for you to kind of not have the stress of work. But I don't think it helped me because I enjoy my work and because um… I then found myself in a situation where I was starting to get quite depressed… lonely and depressed and frustrated and… quite miserable so I don't think it helped me that much.

This institutional exertion of power that was exercised through her medically approved sick-leave did not account for the chronic nature of her symptoms (Glenton, 2003; van Hal et al, 2013). Recovery was not effectively found through this treatment route, and she faced

isolation and psychological distress as a result. Michelle had to use much social capital to negotiate with the medical practitioner, who was enforcing the recommendations, to allow her to increasingly return to work (Giordano and Lindstrom, 2010). The mismatched displayed here is found in the accommodation made by Michelle's employer, which initially appears to be supportive of her and her illness experience, but is enforced so rigidly and narrowly that it fails to account for her desire to work, and the fulfilment she finds in her occupation. Furthermore, in having to negotiate with the company doctor, Michelle was attempting to redefine the parameters of her 'sick role', in trying to return to work and show that she was capable despite having an illness (Blaxter, 2010). She found the recommendation of total rest and minimal work to be detrimental to her wellbeing. This occurred in a context where her work was her sole source of social interaction and network, as she was away from home, and so being made to stay away was unhelpful to her in that regard (Graham et al, 2008).

While she was able to recover from that episode, the sick-leave recommendation reduced her condition to a one-dimensional entity that could be addressed through a single response. Deviation from their recommendation constituted breaking the law. This also shows the multi-level interactions of institutional power, where Michelle's workplace accommodation was reinforced by her employer, her company doctor, the policies and laws of the Netherlands. Dumit (2006) explained the power of "facts" in shaping patient identity and legitimacy, as well as the interactions between institutions, practitioners and individuals. While Dumit's (2006) focus was on the denial of healthcare for conditions that are characterised by uncertainty, the misinterpretation of "facts" in Michelle's illness produces a similar discrediting experience for her. For Dumit (2006), "facts" are meant to clarify the boundaries of sickness and care, but in conditions that are marred by uncertainty; these facts are manipulated in a manner that serves to frame and engage institutions and patients in unproductive relations of contestation. This is illustrated in Michelle's case because, despite having a diagnosis and being offered care and support from her workplace, she does not feel assisted, as the recommendations for treatment are excessively rigid and strictly enforced.

In this context, there was insufficient flexibility and nuance in understanding the nature and needs of Michelle's condition, leading her to feeling unsupported in her illness experience

(Skuladottir and Halldorsdottir, 2011). This occurs despite the attempts made by her employer to accommodate her. By monolithically applying the recommendation of total rest and minimal work, Michelle's employer did not account for the extent of her capacity, or desire to work despite being ill. The frustration felt by Michelle related to Arnold et al's (2008: 119) participants, who saw that a "loss of former identity was strongly linked with loss of a job and the inability to pursue one's long-term career interests". Absence from the workplace was difficult for Michelle, partly because of the perceived compromises she was being forced to make, as well as the mismatch between her identity as a capable worker and her current abilities that were hampered by her condition (Hussey et al, 2004).

In the interview, she later spoke of a colleague who had complications resulting from menopause set off by an encounter with cancer, and reflected that the status of a condition was also pertinent to her employer's response to the sick individual (Werner et al, 2003). Michelle was adamant that if she had taken the diagnosis of fibromyalgia to her employers, and requested sick-leave, there would be nowhere near the level of accommodation she experienced in her seeking treatment for her neurological problems. She commented that,

> I mean it would be interesting also if you took my… me… and took away the brain attack element and just said ok here's a person with migraines and… fibromyalgia or just fibromyalgia and maybe headaches. I… No. no, no, no, no, no. No. that, I wouldn't get a day off. But because I, I had this kind of brain attack and I was on such heavy medication and they had a letter from the neurologist and the letter from the psychiatrist and so on… they then sent me to the neurologist and psychiatrist in the Netherlands and there it was… "this is a very serious condition, you could have another attack where you could have permanent brain damage, we're not messing with that, you will ease back into your work over six months and you will only work 12 hours and we'll see you next month". And that's what I did but they… the day I was allowed back to work I took a whole lot of colleagues out to go and celebrate because I was then allowed in the office and… being treated as a normal person again because also while I was sick I was not allowed to leave the Netherlands. You're sick and if you're not… that's the other thing… if you're not well enough to…. Spend your time at work you can't be well enough to go off and have holidays outside the country. So you stay at home. You don't go. And again in my case because I was South African, it was a very extreme thing because I had no family there and so most people in my situation in the Netherlands would be resting with their families and have their network and so on. So they're very clear, you're at work, you work. Don't bring your illness into work. You… separate…

> and when you're sick don't take your work into your sickness and they believe if you mix those two you actually will be sick longer. So they're very strict about that. They drew two circles for me. And they said "Michelle, we are telling you not to bring your sickness into work". Um… "we're telling, we're saying that you're primarily in here, you're sick and we're saying do not take work in there. We don't want you to… and at the same time we're saying to you, when you're supposed to be working you're supposed to be better, don't try and bring in that you're not fully recovered" and so on. "You keep those separate. And we expect you to be better, and a hundred percent better because we've allowed you this time to recover a two days, and to get better properly". So they're very strict about that sort of thing.

Chloe showed the problems associated specifically with fibromyalgia, and the lack of accommodation found with her employers in addressing the inconsistent and challenging nature of the condition. Chloe's experience confirmed Michelle's perception, that fibromyalgia as a diagnosis would not be afforded the same level of response the latter had in addressing her head attacks. This could have occurred because of the generally low status fibromyalgia as a diagnosis has in the medical hierarchy of diagnoses, or the recognition of the condition in broader SA health discourse (Album and Westin, 2008; Namane, 2013). The infrequent appearance of the symptoms, and their manifestation in the context of stress, meant that instead of sickness being acknowledged, and care and accommodation being dispensed, Chloe was deemed an unreliable employee and forced to seek alternative employment options. Her experience was similar to those descriptions offered by Arnold et al (2008) and Dumit (2006).

Chloe was a 23-year-old woman from Johannesburg, and she had to leave her job as a writer and move into free-lance work to accommodate her condition. In talking about her interactions with her former boss, she related that,

> **Chloe:** 'Cause she's not a very compassionate person at all. 'cause she's very much like "You do the job regardless of what's happening" with very little leeway kind of thing. And I didn't want to tell her at all. Ja, that emotional thing comes up. Often, like I cry or… I get kind of grumpy about it and defensive or whatever… it's not how I like to deal with things. So… when it does have to happen in the moment… I think I fight my emotional responses so much that it comes out as something else or I become even more emotional…

SC: Ok. That makes a lot of sense. So what happened with your boss?

Chloe: Um… well that particularly bad two days where I couldn't move and stuff… that happened while I was supposed to be at work. And… I obviously had to explain it to her, explain why I wasn't at work. And why… I could do the work but it was probably best if she got someone else to do it, for just the quality. I can, I can work, even if it's really bad, I can. It's just not… if I'm editing I'm going to lose a couple of commas here and there.

SC: And it's not necessarily to the standard you want it.

Chloe: Exactly. Ja. It's probably of a higher standard than you can expect from a lot of people but it's still not what I like to produce. Um… and she was not really all that sympathetic and what happened was I was called into the office afterwards… and I find out that my boss actually, the big boss… I was dealing with the GM… the big boss was also there and it turns out that she has fibromyalgia as well… Hers is mostly a manifestation of exhaustion, not pain… but… so she understood and there was sympathy but there's still that whole "you're a subordinate junior and therefore you need to… this needs to be of a certain standard, regardless". Which is actually why I'm free-lancing now, I'm not…

SC: Because working there wasn't something that was conducive?

Chloe: Ja. I need flexibility. If I am having a particularly bad fibromyalgia day… there is nothing I can do about it and I will do my work to the best of my ability and try not to make it anyone else's problem but I have to do that from home, and it is a very important distinction.

In the above passage, Chloe discusses her reluctance to disclose the fact that she has fibromyalgia, and that her condition limits her ability to perform work to the standard both she and her employers expect. Her reluctance was reflected across the narratives of other participants, as they were fearful of the image that would be projected through the knowledge that they had an illness. Stigma associated with illness identities is not uncommon (Scrambler, 2009). While this theme is explored more fully later on in this thesis, it is worth noting here that many participants feared rejection and de-legitimisation of their experiences and particularly their identity as a capable, hard worker. In the workplace, it was important for the participants to maintain an untarnished identity, in that they perceived the disclosure of their condition to be a potentially discrediting act.

Karen, a 25-year-old interior design lecturer from Pretoria, captured this concern in reflecting on the necessity of describing her health status on her CV. She noted that,

> You know you get on your CV… you get like your name, your sex, your date of birth and then they have your health and then you have to say excellent or moderate… like, do you have to put it on your CV? Like, is it so… is it such a big deal that you have to put it on your CV? Ja. Like, I don't want… fibromyalgia to be… a big part of my life… I don't want to feel like I have to… manoeuvre around it even though we are doing it. I mean I am constantly being aware about it. But I also don't want people to, when they see my CV; it's going to be like a red flag going off saying… "Oh should I… should I, should I not, like am I going to have to deal with this person who has a health problem?" Like, obviously you take the best… of the heap but if that is going to be your chance of losing a job or not or being able to apply for a job or not, I'd rather not put it on my CV.

Chloe had wanted to keep her diagnosis concealed from her employers, but in the scenario of being unable to complete work to a sufficient standard, she was forced to produce a reason (Hansson et al, 2006). In explaining herself to her bosses, the exact fear that Karen spoke about in her narrative came to be for Chloe, as her employers were unwilling to accommodate the difficulties and demands associated with her fibromyalgia, which necessitated a move for her into free-lance work. Chloe also noted that despite her employer having fibromyalgia too, there was very little understanding and sympathy afforded to her, and they were unwilling to be adaptable to her (Cohen et al, 2011).

Chloe expressed the need for flexibility that is inherent in managing fibromyalgia, in that she had come to know the patterns of her fibromyalgia, and had identified that working from home was an essential part of coping with the illness experience (Travers and Lawler, 2008). When working as a free-lancer, Chloe felt she was still able to produce the work required, and could do so in an environment, and in a manner, that allowed her to manage her fibromyalgia appropriately. The challenge that emerged from this was reduced financial security, which consequently meant she could not access private medical aid schemes, which in turn limited her capacity to seek help from healthcare practitioners.

Being adaptive and accommodating in facing fibromyalgia was a critical part of coping with the condition for many of my participants. What is also evident in the above narratives is the recognition of the presence of fibromyalgia, and the patterns that can be identified and responded to, when acceptance of their state of health has come to the individual (Richardson et al, 2006b). As elaborated on in the methodology chapter, the point at which I was speaking to my participants was when they had all gained some distance, and were largely coping with their symptoms, and had normalised the condition into their lives. This indicated a readiness to talk, and showed that many of them were speaking through quest rather than chaos narratives, although there was much movement between the two forms during the interviews (Frank, 1997). Many of the people I spoke to had developed a range of strategies and routines that they knew worked in their favour to manage their fibromyalgia. This emerged in the course of needing to cope, in order to live with the condition.

Identifying the parameters of their condition, what was causing which ailment, and figuring out strategies for successfully living with fibromyalgia, all came with accepting broad explanatory categories, holistic labels, and approaches to health and illness and intangible prognoses (Travers and Lawler, 2008). This study confirmed that fibromyalgia is a complicated, unpredictable condition which requires much flexibility. Responsiveness is necessary on the part of the practitioner and patient to effectively address the apparent and anticipated symptoms associated with the illness. The current position of fibromyalgia as a diagnosis is relatively stable, despite its low status on the medical hierarchy of labels. The complications arise from the fact that there is less known about the specific causes, prognoses, and treatments surrounding the diagnosis, all of which traditionally lend a condition legitimacy (Dumit, 2006; Sim and Madden, 2008).

While patterns appear in the morbidity and symptoms of fibromyalgia, there are no guarantees, and expectations and predictions are hard to form for the condition (Deale and Wessely, 2001). This is common with many other chronic illnesses, but, as seen here, it is highlighted particularly in the case of fibromyalgia. This presents a further challenge of recognising, overcoming, and managing the symptoms that appear in the experience of the illness. Additionally, there are risks of delegitimation found in embodying the identity of a fibromyalgia patient (Richardson, 2005; Nielson et al, 2010). While there is awareness that

fibromyalgia is not fatal, the chronicity of the condition, and the disparate and random appearance of symptoms, regardless of "triggers", make responding to the illness evermore challenging. It is argued here that the lack of clear prognosis for the condition undermines the credibility of the diagnosis of fibromyalgia (Cunningham and Jillings, 2006).

As the symptoms endure without effective treatment to reduce their severity, so too do people living with the condition begin to question the applicability of the label, and its potency in explaining the reason for their pain and exhaustion (Nettleton, 2006a). The insecure and insufficient explanation of the prognosis undermines the overall credibility of the diagnosis. This was a core finding of the research detailed in this thesis and contributes to shifting the focus around the location of uncertainty and delegitimation from diagnosis to prognosis. The unclear prognosis of fibromyalgia in turn pushes the person experiencing the illness into a state of chaos and confusion until strategies for adaptation and management of the condition can be discovered and put into effect. At its core is a paradox: while diagnosis serves to establish expectation of meaning, of behaviour, and of outcome, fibromyalgia operates contradictorily to this process as it is characterised by unpredictability and unknowns, with both symptoms and causes appearing disparately.

Acceptance and support were crucial for overcoming the worst stages of the illness experience of fibromyalgia. In adjusting to the altered lifestyles and behaviours needed to cope with the condition, there was a definite sense of empowering oneself to validate the demands of the illness, and to accommodate them (Travers and Lawler, 2008). This is discussed in this chapter under the theme of sickness, and later in the thesis in the chapter entitled "what works and strategies for success". From the narratives collected in the course of this study, there were clear examples of the disempowerment experienced in the medical encounters of seeking diagnosis, both at the point of seeking a label, and then later searching for an explanation, meaning and relief for symptoms (Aujoulat et al, 2007). Many of the people I spoke to had additionally experienced disbelief from their colleagues, families and peers who could reconcile neither the appearance of wellness, nor the infrequent manifestation of symptoms that are characteristic of fibromyalgia, with the notion of genuine

sickness (Werner et al, 2003). This response in turn led to the participants being increasingly insistent, and later strategic about sharing their diagnosis, particularly in interactions within the workplace, where fears of anticipated stigma and discredited identity as a hard worker were prevalent (Scrambler, 2009).

Part of the difficulty of capturing and addressing fibromyalgia experience is the total shift in conceptualisation of what illness looks like, what it means, and what should be done in response to it. Participants in my study who had found practitioners that were able to account for their symptoms, and explain them in a holistic and reflexive manner, and offer treatments that were tailored to their individual needs, fared well in adapting to their condition. Those participants who felt abandoned by unhelpful practitioners who gave little more than a label in their consultation adapted less well (Carlson, 2000). Participants had to feel empowered and able to accommodate their illness in their lives, with the support of their families, workplaces and healthcare institutions (medical practices and medical aid schemes particularly).

Those who felt supported found that making the necessary changes to their routines, home lives, and working conditions was easier than those who found obstacles at every turn of their illness experience (May, 2005). This is discussed later in this chapter with reference to acceptance of uncertain prognosis and the notion of "taking responsibility". There are definite successes in reducing the severity of fibromyalgia symptoms associated with accepting the condition, and being able to accommodate the experience into one's life, thereby normalising it. However, fibromyalgia is a continually challenging experience, fraught with complications and chaos, with new and shifting aspects appearing frequently (Jackson, 2005). This is related to the multiplicity of fibromyalgia, in that it appears alongside other conditions in a spectrum of illness, and can be felt as the dominant feature or as an exacerbating, background aspect of sickness (Schachna and Littlejohn, 1999).

Overall, within the sample included here, those who had had fibromyalgia for a longer period of time, and were older, had mostly recovered from their symptoms. They were now facing new challenges in their health schemas, rather than constantly swimming against the

overwhelming tide of constant pain and exhaustion. Pain and illness were now localised, specific, and had identifiable sources as opposed to the vague, general sense of being unwell that is attributed to fibromyalgia. There were multiple levels of complication embedded in getting a complete view of what fibromyalgia constituted, and the possible routes of response available for the condition (Raff et al, 2014). The most relevant aspect, for the participants involved in this study, was access to private healthcare provision through medical aid schemes. Additionally, finding practitioners who had knowledge of fibromyalgia, and were able to treat it appropriately contributed to the complexity of the illness experience.

The first issue is specific to the SA context, where the majority of specialists and doctors operate in the private healthcare sector, and access is limited to fifteen percent of the population who have medical aid insurance schemes that help pay for the expensive consultations, tests and medications (Mooney and McIntyre, 2008). The second is a broader, globalised problem associated with the status of fibromyalgia in the medical discourse of diagnosis, which largely marginalises those conditions which fail to be explained through biomedical indicators and knowledge (Dumit, 2006; Mik-Meyer and Obling, 2012; Album and Westin, 2008). This consequently impacted on the participants' abilities to seek care, find acceptance and support, fully accommodate the experience in their social lives, and begin to address their illness as a chronic, normalised condition.

From this perspective, it is clear where the breakdowns begin to occur in addressing fibromyalgia as a condition and illness experience. The condition is relatively easy to diagnose, where there is an articulate patient, a recognising practitioner, and accessible healthcare. However, there are missteps found in explaining the condition fully; its mechanisms, causes, explanations and (importantly) effective treatments (Arnold et al, 2008; Jutel, 2010). Because of the lack of correlation between diagnosis and treatment that reduces symptoms to manageable state, knowing what the condition entails, and how to respond to it, becomes arduous and unpredictable. In this process, there is room for scepticism to creep in; within the medical encounter, during social interactions around the condition, and in one's embodiment of the illness (Cunningham and Jillings, 2006).

Expanding the view of prognosis as a site for understanding, explaining, and absorbing the condition of fibromyalgia is a useful exercise, which was displayed extensively in the narratives related by people involved in this study. For them, the emphasis was less on understanding the specific causes of the condition. Rather the focus was on the urgent need to find relief from symptoms and interpret the patterns of the illness, so they could respond efficiently and effectively to fibromyalgia in their lives (Skuladottir and Halldorsdottir, 2011). This was a process fraught with complications. However, it does reflect Christakis's (1997) explanation of conditions that prove to adhere atypically to the typology of diagnosis and assumed prognosis with effective treatment options. The narratives show that there is greater value in giving attention to understanding the trajectories and prognoses that can be offered in order to encapsulate and address the experience of these illnesses.

Liminality, treatment efficacy and renegotiated self

Conditions like fibromyalgia seriously challenge the biomedical approach to understanding health and illness, as the aetiology of the condition becomes more difficult to identify, categorise and deal with within the existing conventional paradigm (Carlson, 2000). The status of a condition (both medically and socially), and the ease with which the condition can be identified and appropriate treatment prescribed, plays an important part in shaping the patient's experience. This is not only seen in the attempt to alleviate symptoms, but also in affording them social and medical credence for their illness. The liminal state of not knowing the causes for illness, or the responses that are effective for reducing the severity of symptoms was a challenging point in my participants' illness careers with fibromyalgia.

Finding an appropriate practitioner and an explanation that made sense were two critical junctures that positively impacted on their illness experience, in that they could find meaning in their symptoms and take the action (Werner and Malterud, 2003). Realising that there is a loose but definite pattern within the manifestation of fibromyalgia was another important stage of overcoming the apex of fibromyalgia experience (Travers and Lawler, 2008). Recognising that symptoms disappear and reappear cyclically, and in response to specific periods of overwhelming stress (environmental, work-related, emotional, physically or psychological) allowed for greater acceptance for the participants of this study. Being

adaptive to the condition and its demands meant that massive changes to work and social life needed to take place, with the condition and the individual's health taking priority over other concerns and roles (Ax et al, 2001).

This was challenging for my participants, as much of their social activities and roles were directly tied to their self-image. In having to scale back, take care, and exist within the constraints of their condition, they felt the loss of their former identities acutely (Sim and Madden, 2008; Miles et al, 2005). For instance, Claire spoke in her interview about how much she hated living within limitation. She explained that,

> I think that's why I hate this thing so much. With every fibre of my being. It's coming face to face with the reality of that limit. Is… it's kind of like… and this is kind of an idea that I've had from maybe when I was like 23, 24… is that my body just does not align with the life I want to live and it's just continually running into these… flipping physical limitations that… it's like, the pain I can live with, the pain is awful, but I can live with it. It's the fatigue. It's the not having the energy to do stuff… and its… looking back… and knowing that other than the 17 years that elapsed from when I was 20, is just I'll never have the energy again. I'll never be able to be that involved in sport and fitness and that, like ever again. It annoys me that most weekends I need to have an afternoon sleep because if I don't, the week's going to be bad. So it annoys me that I have to live this life in limitation. And I hate that.

Claire has excellent understanding of her condition, having found a practitioner that recognises fibromyalgia and prescribes medication that is assistive. Her practitioners have been supportive of lifestyle changes that enable Claire to experience the symptoms less frequently, and with less severity. However, in knowing where her limitations are, Claire is frustrated in her lack of capacity brought on by the condition, and that pushing beyond what she should do means that her state of health will be consequently worsened. Reconciling who she wants to be, in terms of her career, herself as a parent and partner, as well as her memory of herself as an athletic person, with who she is in the confines of her condition is a process fraught with despair for Claire (Miles et al, 2005).

Even in knowing the parameters and meanings of her condition, as well as having good knowledge sources and effective treatments to utilise in navigating her condition does not exempt Claire from finding the experience difficult and riddled with complication (Crooks et al, 2008). She constantly has to justify her health, not just to herself, but to those around her too, as her parents and ex-husband are fairly disparaging of her condition and the means through which it is treated. The general alterations to lifestyle that are core to fibromyalgia treatment are deceptive for people surrounding those with fibromyalgia, as most people are aware of the health recommendations to rest, eat well and exercise (Richardson, 2005). However, for people with fibromyalgia, these simple changes have been found to make a significant impact to avoiding the onset and exacerbation of symptoms (Derman et al, 2011). For instance, avoiding tasks that pressurise either the person or their body unnecessarily makes a vast difference to the frequency with which they experience symptoms. This can involve disregarding previously held social roles and expectations, but in the context of managing symptoms, it is deemed necessary (Råheim and Håland, 2006).

For Connie, not being able to do the housework because of her condition was incongruent with her view of herself as a wife when she was newly married. She related in her interview that,

> All of these things that Dr. Erasmus is saying, it's true for the reason I'm saying it's true is, he said to me if I can't do something I must leave it. Now I'm married I must do my own ironing, cleaning, you know these things. And I feel so embarrassed because the lady will come on a Saturday and I will jump in and she will do the windows from the outside and I'll be doing them on the inside and I will go for a tea break and sit for ten minutes, just ten, and when I have to get up from there I can't get up. I'll be walking like this. Like this. Holding the walls. I can't straighten myself. I can't move. From my neck here, back, everything. I can't move.

In wanting to fulfil domestic duties in line with her role as a wife, Connie ignored the recommendation of her doctor to avoid unnecessary tasks, and having done so, she found she was unable to recover normally (Stavropoulou, 2011; Graham, 1984). Recognising the limitations of capacity was a difficult, but important stage in the illness experience of the participants. This was because it was a gateway into managing the condition, by recognising what tasks were necessary, which activities were worth pursuing, and which interactions with

people were productive for them. This is discussed further in the theme of "what works and strategies for success".

As discussed in this chapter, addressing fibromyalgia requires flexibility, on the part of the patient, their practitioner, and the health system and society they all operate within. Many of my participants spoke about the barriers encountered in accessing treatment, and coping with the unpredictable demands of fibromyalgia. They also discussed the strategies they developed for living with the condition when they had accepted the prognosis, with its inherent uncertainty. The obstacles that were presented to those living with fibromyalgia, described in the course of this study, largely related to circumstances where a typical 'sick role', and the attached recommendations and expectations, were being applied by the patient, their practitioners, their workplaces, and families. A discontinuity developed between the inclusive, adaptive, and flexible approach needed in addressing fibromyalgia as an illness experience, and the narrow, exceptive, and rigid nature of the traditional 'sick role' being applied in response.

This incongruity was felt on many levels, from the individual to the institutional. It resulted in the person living with fibromyalgia receiving insufficient accommodation and care to effectively overcome their symptoms, and assimilate and convert their illness to the status and experience of a chronic condition in their everyday lives. The mismatch also reflects a broader criticism of the Parsonian view of the 'sick role'. The confines of the definition do not adequately account for experience of chronic illnesses, particularly those that inherently have many uncertain components of diagnosis, prognosis, and treatment (Glenton, 2003). The research undertaken here used the narratives of people living with fibromyalgia, in order to explain the interactions, experiences, complexity and challenge involved in accepting and adapting to the condition. This was done as a means to further Edwards and Gabbay's (2007) approach of using the narratives and experiences of those living with a condition to shape and direct responses from practitioners, workplaces, institutions and support networks. The next chapter explores these themes more deeply, and locates these interactions around legitimacy and the 'sick role' in the broader context of the illness career of a person living with fibromyalgia.

Sickness and the Illness Career

Based on the literature and the findings of this study, it emerges quite clearly that what happens, following the initial encounter of the medical practitioner diagnosing a patient with fibromyalgia, is an arduous journey for the person with the condition. They enter a liminal state where they have a label for their experience, and a general understanding of the nature of their condition (Mendelson, 2009). However, there is a lack of clarity and certainty about how to respond appropriately to the diverse and sporadic symptom manifestations. Additionally, many treatments offered prove to be ineffective, and often come with iatrogenic side effects that can worsen their state of health further. As there is so much about fibromyalgia that is obscured from biomedical view beyond the diagnosis, practitioners and patients struggle to move forward in overcoming the severest of the symptoms, and restoring functionality and wellbeing to the person (Dumit, 2006; Barker, 2011). In this context, it is apparent that unique combinations of particular factors are critical in assisting a patient with fibromyalgia through their illness experience. These include: a patient who is articulate, a practitioner who is cooperative and will acknowledge the legitimacy of fibromyalgia, an accessible healthcare system, and a social network that can provide support to this patient.

The above is evidenced by the narratives presented throughout the study explored in this thesis. In investigating the illness experience of fibromyalgia, it became apparent that for many of the participants of the study, getting to know fibromyalgia as a condition was also a process of getting to know themselves (Bieber et al, 2006). This route often involved a reassessment of lifestyle, beliefs, behaviours, perceptions and interactions, as illustrated by Travers and Lawler (2008) in their study of CFS.

While medical knowledge and practice was invaluable in recovering from fibromyalgia, and appropriate treatment critical in managing the symptoms attached to the condition, so too was the responsibility for care taken by the individual and their social network. The participants often needed to reduce the number of people they interacted with, limit social activities and work stresses, and change their image of themselves in adapting to the demands and

constraints of fibromyalgia (Meyer, 2006). This was done while trying to project a prognosis of fibromyalgia, and finding ways to be acceptably "sick", or legitimately enter into the 'sick role'. There was resistance, acceptance, success, and failure in many of these aspects, a theme that is explored more fully in the "strategies for success and what works" chapter of this thesis (Vowles et al, 2009). Part of making sense of the experience of fibromyalgia involved translating the complex, inaccessible information that surrounds the condition, into terms and explanations that were relatable, understandable and generated acceptance (Price and Walker, 2013).

Only a few used the medical explanations offered to them by their practitioners during the diagnosing process. Many others had developed a lexicon and common framework which could easily describe their condition and, importantly, what it meant and involved. As fibromyalgia is a medically ill-defined condition, and many of the symptoms are difficult to account for, it is necessary for the person living with it to be articulate and strategic in utilising the label, and in telling practitioners, peers, family, colleagues and employers about their illness (Werner and Malterud, 2003). The characteristic, overwhelming type of pain and exhaustion called fibromyalgia, is beyond the conceptual grasp of many of the practitioners, health systems, and people interacted with in the course of the individual's illness experience (Richardson, 2005).

People who live with fibromyalgia are often forced to keep proving the severity of their symptoms, and the reality of their experience. This is due to the lack of clarity surrounding the condition, its manifestations, trajectories, explanations, and treatments (Dumit, 2006). For some participants in the study, the frequent questioning of their symptoms, condition and identity was frustrating and limiting in adapting and coping with the illness. Frances, a semi-retired veterinary nurse from Kwa-Zulu Natal, identified an important factor that makes fibromyalgia a significant, but misunderstood condition. She noted that, "the problem is it cannot be measured. It cannot be measured. And that is just so maddening. Because people think, oh well, how bad can it be? You know… I mean, there's nothing to see".

In the above statement, she is reflecting on the disjuncture between receiving recognition and support for the fact that she lives with pain and exhaustion, but the lack of visible severity reduces her capacity to receive empathy and care from those with whom she interacts (Richardson, 2005). It is a continuous problem with diagnosing fibromyalgia, and assigning prognosis, treatment and care to those living with the condition. This problem refers to the fact that a label can be offered to identify the experience, but the scope, scale, and outcome of the condition cannot be concretely seen (Madden and Sim, 2006). Therefore, responding to the condition, and those who experience it, is a process fraught with complications. Consequently, people with fibromyalgia need to become very articulate, strategic and insistent in relating their experiences to others, as shown through the narratives collected in this study.

It seems that in drawing on medical knowledge and explanation, there is clear legitimacy transferred from the doctors' rooms into the social interactions of those living with the condition and their social network (Lupton, 2003). While there was a desire among my participants for a greater measure of specificity, to pinpoint the causes and manifestations of fibromyalgia, there was also space to explain the condition through the understandings gained in their interactions with healthcare practitioners. Having been diagnosed 18 years ago, Frances explained that her medical background and status within her peer group afforded her authority in describing to those around her, what fibromyalgia was, and how it could be understood. She related that,

> I think maybe that's because… I mean, friends that I explain it to have always known me as to be able to… in a group of friends, I was always the one that they would come and ask to have explained why their child was sick or… all that sort of thing because that's always been… a deep interest of mine. Any medical, veterinary, physiological explanation. So they have tended to accept it from me because they know that I tend to know about those sorts of things. I don't know that everyone would find it as easy… Um… ja… but I tend to tell people that it's not something I can explain, because the doctors don't know the reasons either. So I'm certainly not going to be able to explain.

For other participants, there was an acceptance of the condition at face value, in that a basic description of the condition, and what living with it entailed, was a sufficient explanation. It

allowed the person living with fibromyalgia to access a modified 'sick role' where accommodations were made and understanding was forthcoming (van Hal et al, 2013). Zainab had lived with pain for more than 20 years. She had largely adapted to her condition, and was coping relatively well. She was strategic about how she presented the information and to whom, and had experienced derision for her illness in the past. This was reflective of Travers and Lawler's (2008) notion of the Guardian Response, where interactions and activities were managed in order to prevent the onset of symptoms.

As she had normalised the condition into her health schema, her need to tell other people about the condition, and explain the components and nature of it, diminished. She explained that she didn't really talk about fibromyalgia anymore because,

> it's now sort of second nature to me… I don't… its only when… I really feel down and sick and I just tell my family, well it's just… basically symptomatically, you tell them what's wrong. I mean that's my extended family. But my immediately family, I think with my two daughters they… they understand now what's… they understand the whole… condition.

The differentiation between what she will share with immediate and extended family is key to understanding how people living with fibromyalgia draw on support from those around them. With her daughters, Zainab has confidence that they know what the condition is, and what it means, and they can be relied upon to respond to her appropriately. With her extended family, Zainab prefers to explain her symptoms rather than the condition, because she feels they might not understand what the condition denotes, and that she might experience misunderstanding and a lack of support from them (Åsbring and Närvänen, 2002). By explaining relatable symptoms, Zainab also uses a familiar framework for talking about her illness, in that she knows it is successful in communicating a surface level of understanding with regards to her health.

Some participants were able to relate the problems encountered, when recognition and support is not proffered, and how this contributes to the challenges of living with the condition. As Helena explained, fibromyalgia "is extremely difficult to live with, and when people don't recognise it and they treat you a little bit like a pariah… they make you doubt yourself, and they have audacity [to say] that you're a hypochondriac and it's all just in your

head". Claire battled enormously with delegitimation from her family, in the face of misinterpretation of the meaning of her condition. This negatively impacted on her ability to draw support and care from them, as she felt she had to continually justify and explain her condition as real and severe (Richardson, 2005). The effects of social support are discussed in a later chapter, but are briefly relevant here because, for Claire, it affects how one is able to identify as a person with fibromyalgia. It impacts how they are able to talk about the experience, depending on the recognition and acceptance they find in their social circle (Gilson, 2003).

During a discussion of her workplace interactions, Claire spoke of her concerns surrounding her image as a person with fibromyalgia. She described an interaction where

> The hospital manager [was] saying [to me], "No we can't let you do this because you know, that illness… we don't know when… you know" and me saying, but what is that actually about? Because… I'm not unreliable. If I have a day where I can't get into work… I don't let people down, I reshuffle stuff… but I feel like, you know, there's this perception that… that… well I actually personally think that they frame it as "but you know, you're ill".

Claire noticed that she was being cast aside for responsibilities, both because she was seen as an "ill" person, and because of the lack of understanding and applicable explanations that characterises fibromyalgia (Greco, 2012). She had disclosed her diagnosis, because she knew she needed a concrete explanation for her frequent doctor visits and expected absenteeism (Higgins et al, 2012). However, she later felt that the diagnosis was used strategically against her, in conflicts she subsequently had with management at her workplace. The institution she worked for was accommodating, however she found management and other staff to be less so, and much of this stemmed from misinterpretations of the form and meaning of her condition (Edwards and Gabbay, 2007).

Part of coming to terms with the illness experience of fibromyalgia, and what could be predicted and addressed with forethought about the condition, was recognising the patterns that symptoms followed. For instance, knowing the signs of heading into a fibromyalgia "flare-up" was an important marker for people I spoke to in my study. This allowed them to

allocate time and space in their working life to let the symptoms play out, to keep them manageable, and therefore reduce the time they were experienced for.

Having been diagnosed with fibromyalgia, many of the people interviewed for this study described how they entered a phase of discovering the parameters of their condition. They noticed that their symptoms could be connected to events, emotional states of being, and environmental factors, as well to other illnesses (Stockl, 2007; Frank, 1997). Finding out that their symptoms (however varied) had a singular explanation, through the label of fibromyalgia, enabled them to begin mapping the manifestation and nature of their symptoms. They could see the patterns it followed and, crucially for them, this allowed them to discover what steps they could take to reduce the severity of the experience of their symptoms. In many ways, what these people who were living with the condition were doing was developing an understanding of the prognosis of fibromyalgia.

They could see what symptoms and illness belonged on the spectrum of fibromyalgia and when the triggers and hints of a flare-up were present (Meyer, 2012). For those who had lived with the condition for many years, the pattern was more recognisable, and could be firmly linked to different factors, situations, explanations, and outcomes. Furthermore, in normalising the experience into daily existence, many found that while they continued to experience the symptoms, the overwhelmingly severe form of them had diminished (Jackson, 2005). A critical point to note in normalised sickness and chronic illness is that, for the people in this study, pain and exhaustion were always present in their everyday experience of fibromyalgia. What fluctuated, though, was the manageability of the condition. This led to seemingly episodic or routine bouts of "flare-up". In this, the symptoms of pain and exhaustion became overwhelming, rendering the individual unable to continue with daily life, and forcing them to seek additional help from healthcare practitioners.

The narratives collected in this study indicate that this is a common pattern with fibromyalgia and other chronic illnesses. Prognosis is a liminal state that exists after diagnosis, when resolving the illness experience is not necessarily possible, and is certainly not guaranteed (Barker, 2011). Being "sick" in the societal sense of the word is also a space of contestation

for the individual, their social circle, their carers, and the health systems with which they interact. A critical challenge for the participants of my study came in the form of requiring chronic medication in order to manage their condition, as well as necessary frequent medical care (Edwards and Gabbay, 2007). This was problematic, insofar as their medical aids (designed to provide financial support for private medical costs)[11] would not recognise fibromyalgia as a chronic condition, and therefore would not give chronic benefit to them.

This meant that out-of-pocket payments for various consultations and treatments added a massive financial burden to an already physically and emotionally costly condition (Coovadia et al, 2009). Part of the problem with this is the lack of boundaries and predictability that could be attached to fibromyalgia. Knowing what condition is causing which symptom, proves to be a hurdle in defining the expanse of illness that is covered by fibromyalgia as a diagnostic label (Baumann, 2003). The sporadic emergence and disappearance of the symptoms also reduces the capacity of institutions, practitioners, and individuals to know what to expect, and how to respond to fibromyalgia. This means that while there is often legitimacy and certainty in saying that someone has fibromyalgia, describing what it looks like, how it plays out, and what to do about is murkier territory, and comes with serious social and financial implications (Stockl, 2007).

Fibromyalgia is also a curious condition, in that the illness appears and disappears unexpectedly, and often without clear knowledge of why. This makes the response to the condition complicated, as the parameters of the condition are ambiguous, and the ability to anticipate what will happen is unclear. Dumit (2006) argues that in negotiating their way into and through the 'sick role', people living with contested illnesses encounter a range of bureaucratic and administrative challenges, which come from physicians, insurance companies, and government. This adds a level of complication and difficulty, often not accounted for in chronic illness experience, but is displayed richly in the narratives of the participants in this study. Ablin et al (2012: 587) notes that, "previous and current life stress play an important role in the aetiology and pathophysiology of FM", and assert that treatment

[11] Medical aids cover a variety of medical expenses from hospital visits, practitioner consultations and prescription medications. However, they are very specific about which conditions will be covered under "chronic care benefit". Furthermore the extent of the coverage for chronic conditions is limited under medical aid.

approaches should motivate "patients to care adequately for themselves by managing the pain and symptoms, regaining functioning and the best quality of life as possible, and looking for a 'new equilibrium' that optimises the chances of recovery". This indicates that part of coping with fibromyalgia is a reassessment of how life was previously lived, and how fibromyalgia can be incorporated and adapted around activities, pressures and stresses.

In simultaneously coping with overwhelming pain and exhaustion, and trying to carve out a legitimate 'sick role' and identity, many of the participants, who deal with fibromyalgia on a daily basis, spoke of the demoralising effect the condition has had on their understandings of themselves and their capacities (Richardson, 2006a). Part of this relates to the way in which health, illness, treatment, and recovery are all reconceptualised in dealing with conditions that have vague aetiologies, like fibromyalgia (Sanderson et al, 2011). Knowing that symptoms are real, that they are legitimate, and deserve medical attention, is a hard notion to maintain in the constant tide of scepticism and stigma that accompanies fibromyalgia as an illness experience (Råheim and Håland, 2006; Cohen et al, 2011). This was demonstrated throughout the narratives of this study's participants, where they spoke about the questioning, challenge and doubt that surrounded their experience of fibromyalgia.

People with fibromyalgia occupy a liminal state of illness following their diagnosis, there is no expectation given of curing the condition, but there are recommendations and routine treatments that are frequently offered (Meyer, 2012; Kalla, 2011; Raff et al, 2014). Understanding the patterns that fibromyalgia follows does not necessarily provide relief for those living with the condition. Defining the 'sick role' becomes a task beyond the capabilities of patients and practitioners alike (Undeland and Malterud, 2007). For example, Alison, who received her fibromyalgia diagnosis in 2008, had carried on consulting her diagnosing practitioner when she was ill, and had a good relationship with him as a result of his ability to recognise her condition. Her doctor had additionally provided treatments and advice that led to her largely recovering from her fibromyalgia. During the second interview held with Alison, she related her experience of having an appendectomy, and in telling what had happened, she also highlighted the strategies she employed to manage her various illnesses.

Alison was a student in her final year, and frequently had to apply for deferred and supplementary exams due to her poor health. Over time, she had learned the rules and regulations surrounding the application process for these exams. She was also aware of the impact of her conditions (fibromyalgia, sinusitis, IBS and migraines), and how her overall health status affected her capacity and ability to continue with her routines and the demands of her studies. It was in the midst of writing her exams that Alison noticed she was feeling unwell. As being ill was a regular occurrence for her, and something that she understood in the context of her fibromyalgia, she went to her doctor and arranged for her exams to be moved (Prior and Bond, 2008).

What transpired in the consultation was that she had a serious, acute illness (rather than a chronic, non-threatening condition), and she was referred to a hospital, so that further investigations could be conducted. She related that,

> **Alison:** Well no, 'cause actually what happened was… the week I was supposed to write was when I went to hospital. And that Wednesday I was writing my second exam, because I wrote the first one on the weekend. And I was writing on the Wednesday, Thursday. And on the Tuesday I felt ill and then I was like… no I'm sure I will be ok and then I was like, no I'll just move my Wednesday exam to like, now this time, 'cause I wrote last week. 'cause then I just make it the supplementary exam and then I'll still have time. Rather do that than be ill… and then on the Wednesday I went to the doctor and he said "it looks like you have"… um… what did he say? Oh, it might be, um, a cyst on my ovaries. So I had to go into hospital… I was like, thank goodness I didn't go write my exam because…
>
> **SC:** It would have just got worse.
>
> **Alison:** Mmm. and then I was like, ok. And then he sent me to the hospital to go get a scan and everything and I was there for like, 5 hours. Had to wait and then to wait for the scans and then I went back to him and there was nothing wrong with the ovaries [chuckle]. and he said no, there was… fluid in the lower part of my abdomen and he said that's not a good sign. So he says it might be my appendix. [inaudible] be worried. He said I must go back to the hospital and get admitted so I can see a surgeon. And that took another two hours. Sat there waiting for like… it just burst…

Alison related this episode of acute serious illness, because it was memorable in how recently it had occurred, but also because her health was otherwise relatively stable. With the help of her doctor, Alison had been able to find both an explanation and treatments that had gradually improved her health, and allowed her to accept, normalise and realise the chronicity of fibromyalgia, and adapt to it as part of her life (Jackson, 2005). As Lupton (2003) explains, there are contradictions found when illnesses do not conform to the traditional view of the 'sick role', primarily in the sanctioning of the sick person as a blameless victim of disease. The morality linked to access or denial of the 'sick role' creates a disjuncture between receiving a medical diagnosis, and lacking a comprehensive medical explanation. This means that the patient is hampered in their attempt to gain entry into the 'sick role' because, following diagnosis, the expected route of resolvable sickness is absent in the case of fibromyalgia.

This then becomes a chasm in creating an identity as a sick person, as the individual is often blamed for their inability to recover. In determining the criteria for inclusion in a legitimate, medically and socially sanctioned 'sick role', there is room to cast out those who do not fit neatly within the categories and expectation of 'disease', as demonstrated by the findings presented herein. In fibromyalgia experiences, attempting to accommodate the condition in one's social, personal and professional life is a continuous challenge. This is because the condition is so elusive in its trajectory, and the responses available are inadequate and inflexible in allowing one to determine the parameters of the prognosis.

As Claire vividly explained, she always felt one step behind; that she could not get far enough ahead of the curve of fibromyalgia in order to see its expansive reach and address it effectively. Arnold (2010: 383) captures the complexity of fibromyalgia perfectly in explaining that it is "associated with substantial compromise in the quality of life, self-reported loss of function, work disability and increased work absenteeism, and higher than expected health care use". In tackling the condition, existing in a liminal state where one is neither well nor sick can provide additional pressure in bringing the symptoms under control. Understanding that recovery is possible, but not guaranteed, and accepting the condition as a normal and continued state of being, also enables one to come to terms with it. There is

renewed ability to recognise the patterns of the conditions, and utilise strategies that bring relief and reduce symptom severity for the individual (Jackson, 2005).

Frances explained that the feeling of empowerment and the ability to articulate and be part of her treatment decisions played a crucial role in an interaction with her local General Practitioner (GP) following a spine operation she had recently had (Werner and Malterud, 2005). She had experienced post-operative complications on a continuous basis as a result of the side-effects of the medication she had taken for her fibromyalgia. She had the knowledge that her body could not naturally produce cortisone, and she had previous experiences of disempowerment while being treated in medical settings. This had led her to be insistent and firm in her position that practitioners must take her concerns and conditions seriously.

She also showed the distinction between being a "chancer" looking for sympathy, and being a genuine, legitimate patient in need of care (Skuladottir and Halldorsdottir, 2011). She contextualised the attitude of her GP through the explanation that the area she had retired to in KZN had an aging population, and that many of the patients would be looking for comfort rather treatment. She differentiated her case from that trend by emphasizing that, while her symptoms were not indicative of something serious, her previous post-operative experience gave her expertise about her illness, and that she knew insufficient treatment would have dire consequences for her. Werner and Malterud (2003) discussed the interactions of people with chronic pain and their health care practitioners, and the "work" involved on the part of the individual in appearing and behaving as a credible patient.

Werner and Malterud (2003: 1409) show that it is necessary to "make the symptoms socially visible, real, and physical" in the consulting space of the doctors' rooms. In this context, the appearance of the correct balance of illness, health, intelligence, and disarray constituted the "work" the patient had to undertake in the interaction. Seeming too well, or too capable, undermines the ability of the patient to gain access to a credible 'sick role', in that they appear to not need it. This balance was problematic for the people involved in this study, as the attempts to downplay the severity of their condition undermined the participants' ability to garner social support and empathy. In seeking help from biomedical practitioners, people

with medically unexplained conditions are often very articulate about their experiences (Mik-Meyer and Obling, 2012). This is because they have had to contend with scepticism, disregard, and lack of care on a continuous basis, as demonstrated through Rebecca and Teresa's experiences of diagnosis disconfirmation, and the assertive occupation of the label they subsequently used.

The unpredictable appearance of symptoms also produces insecurity in the outcomes of patient-practitioner encounters, as the task of doctors and other specialists is to account for visible signs of illness (Åsbring and Närvänen, 2003). Therefore, coming to the interaction and appearing healthy undermines the capacity of the practitioner to diagnose and treat. It also places limitations on the patient to receive the care, sympathy, and status afforded to someone occupying the 'sick role' (Stockl, 2007). There is a fine boundary that determines inclusion and exclusion in the receiving of knowledge, care, and treatment from biomedical practitioners. Conditions like fibromyalgia challenge the conventional trajectory of the encounter by blurring these boundaries, and presenting obstacles in explaining the causes and expected outcomes of the illness experience a person is undergoing (Jutel and Nettleton, 2011).

The label is dispensed, and then space is created to question and challenge the legitimacy of that diagnosis through the invisibility and unpredictability of symptoms (Lillrank, 2003). The variety of knowledge and disparities in the distribution of information around the condition leads to "incomplete biomedicalization", as described by Dumit (2006). For the participants in this study, this was experienced as a discrediting process where practitioners and medical knowledge would be contradictory, which led to instances of diagnosis disconfirmation and patient disregard. As Helena reflected,

> I believe that the one thing fibromites are not, is they are not empowered. The medical profession does not empower them to cope with the brutality of the condition. And I use the word because, in truth, it is a brutally difficult thing to live with. And I think that if you suffer from chronic fatigue syndrome, I think that if you suffer with lupus, I think if you suffer with rheumatoid arthritis, with multiple sclerosis, some of those are more defined and recognised illnesses but I think any illness in which you suffer untold consistent, incessant pain which is highly debilitated by a loss of sleep. The reality with fibromites, when you don't have, when

> your nervous system is essentially raw it doesn't really matter what age you are your body just doesn't cope with. It's like, imagine an electrical wire. Your nerve endings are constantly raw and edgy and you have this constant amplification of pain.

The searing account that Helena offered was underscored by her feelings of incapability, on the part of her as a patient to ever recover sufficiently, and her biomedical practitioners to consistently and effectively treat her symptoms. Consequently, people with conditions like fibromyalgia are open to being discredited by biomedical practitioners, because they do not fit neatly into the categories, routes, and responses that are used in treating the sick. Maintaining status as a legitimately sick person means that the strategic exercise of "appropriate assertiveness, surrendering, and appearance" is undertaken by people living with chronic conditions on a continuous basis, as they adapt their condition into their life (Werner and Malterud, 2003: 1409). This was reflected in the narratives of the participants of this study.

This means that people with chronic, often inexplicable conditions have to account for the presentation they give when consulting with health care practitioners, and this also carries over into their interactions in their personal, social and professional lives. In her interview, Frances spoke about the importance of feeling consulted and part of the decision-making process when it came to her medical treatment (Bieber et al, 2006). Like most of the participants, Frances needed treatment for many other conditions that formed part of her broader illness experience. She related that, having had aggravated endometriosis and exploring different treatment options, she met with a gynaecologist in Cape Town. She explained that,

> He came to chat to me, such a nice man… and he was talking about… treatment and which way we would go and that sort of thing. And the nurse came in and she was an absolute cow from hell… and she came in and she said to the doctor, "so what are we doing to Mrs. Porter?" and he said, "Mrs. Porter will decide what she would like to have done". And I thought, yes, this was… is definitely the way to go. I mean she was absolutely non-plussed… that I should have any choice in the matter. But that, to me, was… what I needed. That was the way I needed to be treated. I need to choose which direction I'm going to go in for treatment… I need to be involved. I hate sitting there and just being… "this is what's going to

> happen". It's empowering. There's nothing more to make you feel like a blob in a corner than just being treated like a… a case file.

In her narrative, Frances reflected a principle of self-care in that she had awareness of her medical history, and attempted to work with her healthcare providers by bringing this prior knowledge to the fore (Audulv et al, 2012). In the interaction detailed below she displays what Gately et al (2007: 940) describe as the trend for healthcare professionals to "value patient involvement in principle, but have yet to embed the facilitation of self-care into clinical practice". Frances explained that she went to her GP,

> And I said… the previous operation I had had pneumonia and pleurisy afterwards. And after the… after the third one, that's right. I went to him and I said I just don't feel a hundred percent at all. And he kind of patted me on my head and gave me a vitamin or something and by the next afternoon I was in ICU in St Anne's because of a chest infection… and he hadn't even bothered… I had related the history from the previous op… and he didn't even bother to pick up a stethoscope and listen to my chest. And I wasn't thrilled with that at all. Um… if I go, I go for a good reason… and I do object to just being… dismissed. And… yeah that was not a good one. But as I say, they deal with a huge geriatric population [in this area of KZN]. And… I'm sure there are times where they think… oh yeah right, they don't feel quite right, you know… they need a pat on the head and somebody to chat to… sort of thing. So… yes I was a bit cross about that… but it happens… he doesn't… ignore me quite so easily these days if I go in and say something [chuckling]. I'm just trying to think what the other occasion was, there were two. In fact… it was another chest infection thing. I'd had bad flu and I'd got better. And then I started feeling worse again… and… I had a strange pain … under my shoulder blade… and the only other… and again I was patted on the head and given a vitamin and sent off. And the next time I had exactly that pain is when I had pneumonia and pleurisy in hospital. So I was pretty sure that I had actually gone backwards and got pneumonia because it took me weeks to get over it… weeks and weeks… so… yes he now expects me to have the unexpected and then expect that to go wrong [chuckling].

There was a clear distinction for the participants between illness episode that could be resolved, and the chronic nature of their fibromyalgia. In the course of the interviews, many of the participants spoke about being "sick" which, for them, was different from fibromyalgia as the latter was an embedded, underlying component of their illness and health experience.

Existing in the liminal space of living with constant pain and frequent exhaustion meant that the boundaries between being well and ill were difficult to view clearly (Jackson, 2005). This is delineation from the view that recognition and legitimacy are the same. While recognition often translates into legitimacy with most diseases, fibromyalgia confounds this process (Stockl. 2007, Barker, 2011). By investigating people's illness experiences and their interactions with medical and political institutions and actors in this process, the relations of power and discourse moving through the experience were effectively captured. This is important in understanding the scene in which people living with fibromyalgia are negotiating their illness, and the role that medicine plays in allowing their experiences to be validated and dealt with effectively. Additionally, it was possible to see how this translates into their social ability to operate functionally within society.

A central component of this research was an investigation of how the deficit in available and effective treatment motivates people living with medically ill-defined conditions to seek out further legitimacy and relief from their symptoms, having received a clinical diagnosis. There is recognition in the biomedical sphere for fibromyalgia as a diagnostic label. Having said this, however, the distribution of meaning, knowledge, and response to the label in broader medical and social discourse and interaction is uneven. This creates uncertainty for the person with the condition, as well as for the practitioner treating them, and the society that the individual interacts with (Barker, 2010; Undeland and Malterud, 2007). Embedded in this, is the notion that legitimate sickness has a time-limit; sympathy and accommodation are only available for a period of time, which ends when the illness is expected to resolve (Nettleton, 2006b).

Conditions like fibromyalgia are defined by the endurance of the symptoms despite their infrequent appearance and fluctuating severity. In this context, there is a need for flexibility in response, which exacerbates the insecurity surrounding the status of the condition, and of the people who experience it. Contrasts made between one's chronic condition and other instances of acute illness amplified the sense of difference and injustice felt by the participants of this study, in interacting with others around legitimate sickness (Gibbons, 1999). Zainab spoke about the breakdown in her marriage, and how her partner found it difficult to be supportive of her in her chronic illness experience of fibromyalgia (Issner et al,

2012). While she could speak to her children openly about her state of health, she noted that,

> It was my husband that… in fact that's a very strange thing because he's actually… when we were married, he actually had two heart attacks. And you find… you know… he's like… I think… because we got divorced in … about 2003… and at that time, I mean, even though he was gravely ill… I was the one with pain and he was the one who could lead a normal life… so it was like just bizarre that, you know…he's the one that needed the attention really, but I was the one that was… you know… so really at the end of the day, even when it comes to relationships, it was very difficult to… you know, be supportive, to… that kind of thing…

Importantly, the visibility and certainty of a heart attack, as well as its position as an acute condition, meant that despite being incredibly ill, life continued for Zainab's husband. He was able to recover and carry on with a "normal life", while Zainab endured pain, but in a less externally visible, life-threatening manner (Lonardi, 2007). She noticed the difference in response to her condition, due its chronicity, which stood in contrast to her husband's experience of a heart attack where he was able to access a legitimate 'sick role' (Nettleton, 2006b). Critically, this happened because his condition reached a resolution, in that he fortunately recovered. As argued by Jackson (2005), the liminality of chronic pain means that because no end-point can be defined, and no firm response can be applied, eventually the credibility of the person's condition diminishes.

Claire, in our second interview, spoke about her recently episode with a head cold, which had a variety of effects on her perceptions of her fibromyalgia. It had made her question the reality of her condition, and the control she had over it in surrendering to the symptoms, and the identity of living with fibromyalgia. She also noticed a stark difference in the reaction she received from her colleagues when she was ill with the head cold (Prior and Bond, 2008; Lupton, 2003). It occurred to her that

> Then I don't have to acknowledge that it [fibromyalgia] is real. So I think for me, like the biggest thing that's stood out is… I think two things; the one is that kind of thing of not really accepting it. And… kind of thinking oh maybe it is just in my head and… maybe I don't really have to take it seriously and whatnot. And then I think the other thing is I had a head cold the other day… and… with the head cold people say to me, "sjoe you look so sick you should go home"… you go like, "this isn't bad compared to how I feel everyday!" And then

> with that then going on cortisone and then remembering… cortisone always makes me feel wonderful. And then remembering what it's like to not live with the pain and the fatigue.

Accepting fibromyalgia into her life was a continuous challenge for Claire on a number of levels. She could not resolve her diminished capacity with her drive to "be a superhero". She also faced scepticism and disbelief from her parents and ex-husband, as they were not convinced of the existence neither of fibromyalgia, nor of the severity and overwhelming nature of her symptoms. In having relief from the symptoms of her head cold, as well as the pain and fatigue caused by the fibromyalgia through the cortisone treatment, Claire was also able to glimpse at what life looked like without the overlay of fibromyalgia symptoms. This experience had created questions around the realness of fibromyalgia, and drove her to reconsider whether it was simply a matter of will, rather than physical incapacity, that led to her being unable to manage and overcome the symptoms. Additionally, the attitude of her colleagues played a role in how she perceived herself and her illnesses. This is reflective of Campbell et al's (2011) analysis of the effects of social support in health and illness experiences, as Claire receives satisfactory support in emotional, instrumental, informational, and appraisal forms for her head-cold. However, she continually encounters disparagement and challenge around her fibromyalgia.

In the case of her head cold, Claire was given sympathy, advice and support; even though she felt that her symptoms were not as severe as the ones she endured daily with her fibromyalgia (Greco, 2012). This also carried over into the illness identity she had with fibromyalgia and with the head cold. This illustrates the different responses afforded to a chronic condition like fibromyalgia, and an acute one like a head cold. The visibility, recognition, accessible response and resolvability of the head cold makes it a more socially and medically acceptable illness than fibromyalgia (Nettleton, 2006b; Jutel, 2010). It also affords Claire sympathy and support in taking time off work to recover, which echoes the expectations and responses associated with the traditional 'sick role' that permeate relations between those who are ill and their social networks (Glenton, 2003).

In contrast her fibromyalgia, despite being a condition with much more severe symptoms, is treated with suspicion and disbelief by the people that surround her. The chronicity of her symptoms reduces the capacity for empathy from her colleagues, and there is real danger in her work identity being eclipsed by her illness identity as someone who is known to have fibromyalgia (Sim and Madden, 2008; Issner et al, 2012). The effects of this anticipated and enacted stigma is explored elsewhere in this thesis, but it is important to note here the outcome that Claire experiences in attempting to be upfront about her condition, and carving out accommodation for it in her work life. Instead of feeling supported and understood, Claire feels that her image as a good, reliable worker is polluted, impinged upon by this contested illness that mysteriously and unpredictably appears and disappears, for no knowledgeable reason (Råheim and Håland, 2006).

Like other people involved in this study, this leads to Claire being cautious about talking about her fibromyalgia, showing her sickness, and giving in to the symptoms. This means that she, like others, conceals her condition as far as possible, only acknowledging symptoms when they are incredibly severe and overwhelming. Having normalised the pain and fatigue into her life, and having also recognised the pattern that the fluctuations of symptoms seem to follow, she is also more capable of responding to the condition, and makes the symptoms manageable through various treatments (Lonardi, 2007). Her acceptance of the condition only extends to her acknowledgement of it as a factor that limits her capacity in work and home life, and is a source of much frustration for her (Bieber et al, 2006). She frequently questions the reality of the condition, but understands that it is the best possible explanation for her experiences. Claire is also aware that her fibromyalgia needs ongoing attention while she is in the liminal space of knowing she is not well, but is also not as ill as she had previously been, or could be without monitoring her fibromyalgia (Ablin et al, 2012).

The debate that occurs in medicine about the legitimacy of fibromyalgia as a medical diagnosis is attributed either to the "arbitrariness in the diagnostic criteria… [Or] from the failure of medical science hitherto to establish a clear aetiology for FMS" (Sim and Madden (2008: 57). As Brown, Lyson and Jenkins (2011: 940) argue, determining health or illness, and identifying what particularly is wrong with the individual's state of wellbeing, so as to render them 'sick', is a relational process. Specifically, they state that the process of

diagnosis is “simultaneously a site of compromise and contestation… [and] when there is a disconnect between the patient and the medical explanatory model, the individual may be unsatisfied with treatment goals” (Brown et al., 2011: 940). Expanding on these ideas by describing the experiences of those diagnosed with fibromyalgia, Sim and Madden (2008: 62) argue that searching for and attaining a diagnosis of fibromyalgia is a pivotal stage in the patient’s illness career, and that “pre-diagnosis represented a difficult and disruptive period”. During this time, a patient might consult with a range of health care practitioners, always searching for a better and more legitimate explanation, to give their experience medical and social meaning, and validate them as a ‘sick’ person.

This was the case for the people involved in the study explained throughout this thesis. It resulted in some of them either dispensing with the label of fibromyalgia entirely, or stating that it was a minor component in their health schema. The shift in use of the label of fibromyalgia generally occurred when the person had mostly recovered from their symptoms, as well as managing their condition through medication, and were drawing on a "quest" narrative when speaking about their illness experiences (Frank, 1997). This meant that the condition no longer impacted on their state of health, their working ability, and social life to the same extent as when they were at the apex of the severest symptoms. In taking fibromyalgia out of the foreground, and relocating it to the background in their illness career, the people who were able to achieve this could be seen to be coping with the condition. As they had resolved much of the uncertainty, insecurity, and confusion that defined many of the earlier stages of their sickness, they had figured out strategies for success and what works - a theme discussed in later chapters of this thesis.

Treatment

This section will discuss the treatment methods and means used by people living with fibromyalgia, as well as the successes and challenges embedded in the process of figuring out "what works" in reducing the symptom severity of the condition. The transformation of the condition from an acute episode of intense and overwhelming pain and exhaustion, into a chronic illness experience that may subside and remerge over periods of time is additionally explained. Consistent with the literature and illustrated in this study, conditions like fibromyalgia struggle to gain medical recognition and legitimacy. In this, there is a simultaneous movement away from seeking support, advice, and treatment from traditional sources of health care (such as doctors), and towards self-care and management of the condition (Audulv et al, 2012). As discussed earlier, there is a lack of knowledge surrounding the manner in which communication around self-care is managed in healthcare interactions (Thorne et al, 2004).

The study undertaken here was able to reveal some of these processes, particularly in relation to the chaotic, experimental approach to treatment that plays out in the attempts to address fibromyalgia in SA. The reasons for this chaos are two-fold: firstly, because biomedicine cannot easily categorise fibromyalgia, diagnose the condition, or offer prognostic outcomes and there is a scarcity of effective treatments associated with the condition. Secondly, the position of fibromyalgia as a chronic condition is insecure. This is because of the condition's relatively low status on the medical hierarchy of diagnoses, sporadic and diverse symptom manifestation and unpredictable trajectory (Werner et al, 2003). The consequences of this, in the SA context, is that medical aid schemes that enable access to private medical care, are unwilling to provide fiscal support on an ongoing basis for people with fibromyalgia.

This is because the chronicity of the condition is unstable, with the disappearance and appearance of symptoms making regulation and patterning of experience and response very challenging for patients and practitioners (Gilson, 2003; Åsbring and Närvänen, 2002). This was evident in viewing the experience of fibromyalgia through the narratives of those living with the condition.

An important issue to emerge from the research detailed in this thesis is that of adequate financial support from medical aid schemes for consultations, treatments and medicines for those living with fibromyalgia. In this chapter, the adaptive strategies that people with the condition utilise to continue their treatments, and cope and live with a chronic illness, are also explored. Additionally, the role of pro-bono treatment offered by the health care practitioners, and the social capital drawn on in manoeuvring around and through the restrictive medical aid schemes is discussed. The continual negotiation of self and sickness through the access of treatments, and ability to cope with the condition, is a prominent theme that emerged in the narratives collected through this research.

Accommodating the condition into one's life was hugely dependent on the ability to access effective treatment that would reduce the severity of symptoms into a state of manageability, where distance from the experience, and perspective, could be gained. Complications with this process appeared in the fact that treatments were not widely accessible, or were only funded for short periods of time. Additionally, people were not only living with fibromyalgia; all the participants in this study had comorbidity with other conditions (Raff et al, 2014; Moch, 2010; Meyer, 2012; Namane, 2013; Butow and Sharpe, 2013). This means that while treating fibromyalgia, people who had the condition were also managing other conditions that required a balancing act of overall health promotion, as well as appropriate medications and treatments to work in tandem in order to cope with their illness. This is in line with what Mody and Brooks (2012: 246) say in their discussion of the fact that countries in the developing world "face additional challenges of smaller workforce and less resources; thus, it is necessary to develop newer models of care which enable maximum benefit even in low resource settings".

This challenge is particularly pertinent in the SA context where, as previously discussed, there are inequitable distributions of healthcare provision, and limitations are found in the availability of practitioners and treatments (Namane, 2013; Padarath et al, 2003; Stuckler et al, 2011; Basu et al, 2012). The effects of privatised healthcare, and the barriers that exist around access to treatment, are relevant for analysis in this thesis in terms of the findings of

this study, which showed that help-seeking behaviour changed in accordance with medical aid coverage. In shaping the patterns of diagnosis, and outcomes of healthcare interaction, it was critical to understand fibromyalgia as an illness experience, in the context of SA. This was important specifically with regards to the approach taken by private medical aid schemes and practitioners who operate in the private healthcare sector in relation to fibromyalgia. It is a key theme explored in this chapter, and is further developed in the next chapter too, entitled "institutional interactions". In the next chapter, the limitations of medical aid provision are discussed for their impact beyond immediate treatment, and into societal perceptions of conditions with insecure credibility, like fibromyalgia.

The findings of this study reflect the literature detailed earlier, and show that in the process of receiving a diagnosis, and in determining a route forward in their illness experience, people with fibromyalgia interact and engage with a range of treatments prescribed by doctors and other health care practitioners. Additionally, people with fibromyalgia draw on the advice and support of peers, colleagues, and family in their social networks in figuring out which treatments suit them best, provides the most effective relief from symptoms, and which are accessible and readily available (Gage, 2013). As with diagnosis, treatment for fibromyalgia is variable, challenging, and fraught with complications derived from the multiplicity and invisibility of the symptoms of the condition (Werner et al, 2003). Fibromyalgia appears in the midst of ordinary life and other illnesses, and is intertwined with lifestyle, behaviours, social roles, and obligations that predispose people to the condition, perpetuates the onset of illness, and (in many cases) also exacerbates the continuation of severe experience of the symptoms (Meyer, 2012; Derman et al, 2011; Houdenhove and Luyten, 2008).

In the process of determining the parameters of the condition, people with fibromyalgia often engage in many forms of self-care, where responsibility for illness and remedy for the symptoms is managed by the individual, with secondary advice and assistance from health care practitioners (Audulv et al, 2012). For example, Karen spoke to her parents before seeking further advice and using treatments to address her symptoms. In discussing narratives of rheumatoid arthritis, Sanderson et al (2011: 618) utilise the concept of "'shifting normalities' [which provides] a dynamic explanatory model of chronic illness that captures the interaction of changing conceptions of a normal life and the normalisation of symptoms".

In attempting to understand a condition similar to fibromyalgia, the explanation of 'shifting normalities' is useful as it illuminates many of the complexities inherent in the multiplicity and interconnectedness found in both experiences of the condition. Fibromyalgia, as shown in this study, is not a singular "event". Rather, it is a continuous process of adaptation and normalisation, where attempts to pinpoint the parameters of the condition and respond to the symptoms are made frequently, in order to reduce the severity of the symptoms and manage the condition. This is discussed later in this chapter, in the explanation of liminality, treatment efficacy and renegotiated self (Jackson, 2005; Richardson, 2005).

The reintegration of pain and exhaustion into ordinary life is also reflective of the phases people go through in their illness experience, as they move from chaos to quest narratives in explaining their illness (Frank, 1997). When the confusion brought on by the contestation surrounding fibromyalgia as a legitimate illness dissipates, there is space for acceptance of the condition as socially and medically real (Cooper, 2002). Having achieved this through the attainment of diagnosis, people living with the condition can embark on a process of shaping treatment regimes that align with the individual's needs and experience of a complex and interconnected condition (Skuladottir and Halldorsdottir, 2011). Experimentation, lifestyle adaptation, practitioner support, as well as institutional response all impacted on the ability of the individual to recognise and overcome symptoms (Kalla, 2011).

Furthermore, in receiving different forms and levels of support and assistance in addressing and living with a chronic condition, there were variations in the coping capabilities of the people interviewed for this study. Unlike acute conditions, fibromyalgia as a chronic condition appeared to be a continuous disruption in the biography of the participants of this study, where health remained a forefront concern despite experiencing symptoms to a lesser degree than when initially diagnosed (Richardson et al, 2006b). The ability to access effective treatment was a prominent factor in influencing the routes and strategies taken by the participants, in reducing the impact of the condition on their daily lives. This refers to both the types of treatments that are routinely available in medical practice for fibromyalgia, as well as the extent of medical aid coverage for people who experience fibromyalgia as a chronic condition.

Liminality, treatment efficacy and the negotiation of self

Of importance to the discussion of treatments for fibromyalgia, are the differential durations of the condition, and the stages people experience in the course of their illness. As already discussed, fibromyalgia can appear as an episode of extreme fatigue and pain, or as a marring, enduring and underlying component of illness experience. It can be affected by predisposing family histories of chronic illness, and precipitated by injury and other illness, or extreme emotional, physical and mental stress. It can also be perpetuated by ineffective medical care and treatment, lifestyle factors, work, family and life strains as well as poor coping abilities (Morris et al, 2011). Inevitably, through the course of addressing, coping with and overcoming fibromyalgia there is challenge and frustration, as the routes of treatment are unclear, and knowledge on the condition is unevenly distributed in medical discourse and sparse in societal notions of legitimate illness (Åsbring and Närvänen, 2003).

The productive and limiting capacities of fibromyalgia as a diagnosis were extensively discussed and analysed through the narratives of the participants involved in this study. Participants related how they embarked on a process of accounting for the form and outcomes of their conditions, now that they had a name for it. This occurred when they had moved beyond the initial consultation where the diagnosis of fibromyalgia was discovered and dispensed. The process was riddled with complexity and challenge and many of the stories offered through the interviews displayed characteristics of Frank's (1997) "chaos narrative". Determining their prognosis and finding the parameters and strategies that could work to reduce the severity of their symptoms proved to be an important stage of recovery.

It was a critical step as it allowed them to transcend the overwhelming nature of their pain and exhaustion. **Acceptance and accommodation** were important in approaching fibromyalgia. The trajectory of the illness experience was not lateral, uniform or predictable. Therefore, much reflexivity and reflection was required on the part of patients and those that assisted them with their condition. Establishing the chronicity of their condition was challenging, as it was not a fatal disease, but conventional means of addressing illness did not

work either. The participants of my study highlighted most strongly the difficulty they faced in converting their subjective experience into recognised and socially sanctioned sickness (Jackson, 2005; Higgins et al, 2012).

In speaking about illness narratives and biographical disruption, Sanderson et al (2011: 619) explain that the process of narrative reconstruction attempts to "establish points of reference between the (changed) body, self and society, reconstructing the past so that it has meaning or purpose for the present. However, these narratives may be continually reconstructed to weave new symptoms, new knowledge of the condition, and new reactions from others into the story". As described earlier, treatment for fibromyalgia is complex and accordingly, practitioners and patients have to be responsive to the condition, the needs of the patient and the limitations imposed through the experience of the illness (Skuladottir and Halldorsdottir, 2011). As mentioned in the last section, the following four aspects contribute enormously to the ability of the individual to live and cope with fibromyalgia:

1. an articulate (and occasionally insistent) patient,
2. a recognising practitioner,
3. an accessible healthcare system and
4. a supportive social network belonging to the patient.

In this picture, there is an additional component that plays a significant role in shaping the health outcomes of people with fibromyalgia, namely effective treatments. This chapter will discuss both the recommended routes of treatment for people with fibromyalgia, but also document and detail those instances of care that have had iatrogenic effects for the people involved in this study (Mease et al, 2010).

Additionally, the failures of biomedicine to account for and explain fibromyalgia in diagnostic and prognostic frameworks, commonly used in health and illness discourse in society, are explored in this chapter. This is included because of the apparent "turn" away from conventional means of treatment, and towards use of complementary and alternative approaches and medicines that were frequently used by those involved in this study. While

biomedicine was predominantly employed in treating fibromyalgia, there were a number of other remedies and practices used by the people in this study to achieve a better state of health. Biomedical and alternative treatments were often utilised in combination. The greatest factor in choosing one method over another was simply a desire for a remedy that worked, that provided relief from symptoms, and allowed the individual to return to a state of health where their fibromyalgia was manageable (Ax et al, 2001). As fibromyalgia is such a complex illness, a holistic approach that encompasses a range of treatment methods and medications was appropriate (Meyer, 2012). The diversity of techniques and treatments were seen to have differential effects, and determining the best route to recovery was a challenge for participants of this study, and was explored in their narratives.

It appears that the ability to cope, face obstacles, adapt and succeed in living with fibromyalgia relied on the capacity of the patient to articulate their experience, and seek out a practitioner who would validate them as a "sick" person. Treating the individual in a multi-modal, holistic approach was also important, as it allowed the individual to absorb the experience of fibromyalgia as something concrete, real, and manageable in their lives (Koch, 2012). Furthermore, taking an experimental stance towards treatment, where generalised recommendations could be individually tailored, and then adapted and assimilated into the patient's life, also proved an important stage in addressing fibromyalgia (Meyer, 2012; Raff et al, 2014). The development of coping *strategies* in treating fibromyalgia also emerged as an important process throughout the narratives captured in this study. The strategies appeared in combinations, which were generally related to stress management (Ablin et al, 2012).

They included:

1. Lifestyle adaptations around exercise routines, diet changes and social interactions
2. Avoidance of injury or further traumas, such as emotional and physical strains
3. Shifts in working environments and relations, in order to promote a more supportive space for normalising and coping with fibromyalgia in their lives.
4. Sourcing effective treatments that allow for the management of the condition, and reduction of severity of the symptoms.

From evidence gained through the narratives collected, the range of strategies utilised by the participants of my study broadly encompassed the pattern of knowing which stressors and triggers could precipitate or worsen their symptoms. This in turn, once having lived with the condition for a period of time, allowed them to recognise the onset of a fibromyalgia "flare-up", and move towards adjusting their life in order to accommodate their illness. Discovering "what worked", and successful strategies for living with fibromyalgia constituted a core stage in the illness career of my participants. Their narratives displayed the fact that dealing with the condition required an immersion of oneself into the experience, in order to develop and see ways through (Frank, 2010).

Much of this process was confronted at the point of diagnosis, where the recognition gained in getting a name for their experience and a framework in which they could explain and understand their condition allowed for recommendations to be made with regards to treatment. In seeking a diagnosis, a patient is also seeking alleviation and remedy for their symptoms. This means that, in hoping for a name and an explanation, a patient is also simultaneously expecting an associated treatment. As described and discussed at length in previous chapters, with fibromyalgia, the trajectory of the patient's interaction with a health care practitioner is severely disrupted by the complex, hidden and inexplicable nature of the condition (Sim and Madden, 2008; Stockl, 2007; Jutel, 2010; Dumit, 2006).

This consequently affects what treatments can be offered, due to the binary relationship of diagnosis and treatment, where the former inherently precedes the latter, and in a medical encounter a patient hopes to leave with both. As explanation precedes treatment recommendation, a chasm appears when the label and description offered fails to capture the nuance, nature, and mechanisms of a condition. This is illustrated in Chloe's experience of receiving the diagnosis of fibromyalgia, but then being prescribed treatment that addressed her anxiety. The medication also had iatrogenic effects for her, which discouraged her in continuing to use it, and promoted her into a further quest for clearer explanation and symptom alleviation.

Additionally, because fibromyalgia specifically appears with a host of other conditions, knowing which symptoms are to be treated, and how, also proves challenging. The gap between what can be seen and explained in fibromyalgia experience extends over to the treatments that can be proffered and be relied on to be effective in reducing symptom severity. Karen reflected on this in her interview when she explained that, in her experience, the attitude from those caring for her was mismatched with what she thought she needed (Skuladottir and Halldorsdottir, 2011). She described how she was told by her parents,

> **Karen:** Like, here, drink this pill, go do these tests. Where… you know, I've established what it is, it's more of… of… working my life around it now. Like I've come to terms where I've actually realised… you know, ok pain is the enemy, but not trying to treat it like the enemy. So trying to be friends with it by not feeding it anymore or… like, ja so…
>
> **SC:** But you're talking about is needing support… not just treatment.
>
> **Karen:** Yes. I mean it's that whole thing of um… you know I don't know what it is, I've read up about it but everyone's so unclear about it and its very confusing because you don't know if the pain is being caused by a mental problem or if it's from the stress or… you know your body is in this jumble of emotions as well because… you moody because you're not feeling pain, but you don't know… ag, because you're feeling pain [she corrects]. You don't know if the pain is coming from depression or from lying down the whole time… like it's still coming to that realisation that you have to put everything together… you understand what I mean? Like putting everything together and saying like listen, it's not this, it's not this, it is this so… this is affecting this part… I mean the stress part is a big part of it and stress has its own little symptoms on the side. But you know, I'm trying to focus on the pain first. 'cause I believe that is where everything is coming from. You know maybe… I am bipolar or something but… you know, that is a whole different degree. Like at the moment I just want to deal with being mobile and being pain free. Ja.

Karen's narrative shows the multiplicity of fibromyalgia, and the confusion she feels around what factor is causing which ailment. She also demonstrates her approach and aims for treatments, which is to improve her functioning, and to address all her conditions in tandem.

Treatment must be holistic, and encompass the patient's physical, emotional, psychological and environmental well-being. For the people who participated in the study described in this thesis, there was not as much of a turn away from traditional biomedical care as the literature

implies. Rather, the interviewees spoke about a dual use of conventional and alternative treatments that frequently complemented one another. The primary concern for the people who participated in this study was to find medications, treatments, practices and routines that would assist them in coping with their condition and alleviate their symptoms. Explanations were sought from many sites: doctors' rooms, the internet and other media sources, peers, family and other health care practitioners, as seen in the analysis of the findings.

In an interview conducted for this study with Prof Meyer, a leading expert on fibromyalgia in SA and a family medicine practitioner working in Pretoria, explained,

> The problem is fibromyalgia is not a homogenous disease, you know, some people have a very light sort of form of a few aches and pains, they take a panado now and a triplene and they [are] fine. Other people, really have got a debilitating disorder and then in between you get a lot of patients who've got strong psychiatric co-morbidity. Anxiety, depression… so you get at least three clusters… the mild type that will present at the GP, the sort of patient that will often present at tertiary hospital. We've got a lot of mental and psychiatric co-morbidities, either in primary or secondary… and then, well there's this third group that hasn't really got psychiatric co-morbidities who already are actually patients who are very strong, active copers. And that's where we think the interesting part lies, you know. There's… we think there could even be a… subtle, sort of, inflammation reaction, those sort of patients' pain. But the bottom line is that it's not a homogenous thing.

Prof Meyer also mentioned the importance of utilising a bio-psychosocial approach to diagnosing and treating people with fibromyalgia. This approach allows for as much coverage as possible, when accounting for symptoms, patient history, psychological and emotional aspects of illness, environmental impacts on treatment response, and health beliefs and behaviours of the patient (Arnold, 2010). As the above passage shows, correctly identifying both the type of patient that is presenting, as well as the nuances of their particular experience of fibromyalgia are critical steps in the process of addressing the condition and seeing ways of coping with it. Prof Meyer's (2012) explanation also emphasises the multiplicity of fibromyalgia, as it presents with psychological co-morbidities and other illnesses. It appears on a spectrum of severity, where a variety of patients experience fibromyalgia to differing extents.

This distinction between mild, overwhelming, and coping experiences of fibromyalgia is a useful typology for explaining the many manifestations of the condition, and allows for clarity in analysing the groupings of people who live with fibromyalgia in SA. Fibromyalgia is generally considered a long-term chronic condition, but there are fluctuations in how much it impacts on normal living and functioning and disrupts daily life. The condition can be unpredictable in nature and difficult to view through traditional biomedical indicators. This means that it is inappropriate to respond to fibromyalgia as an illness experience in a singular and narrow fashion (Sim and Madden, 2008). As with many chronic conditions, fibromyalgia management is a combination of pharmacological treatments and lifestyle adjustments (Arnold et al, 2012). The role of social support from family and peers, as well as institutional responses in the form of accommodating workplaces and financial support from medical aid schemes are important factors in explaining the experience of fibromyalgia in SA.

For the participants in this study the "work" of being a patient often continued long after their initial diagnosis (Werner and Malterud, 2003). The process of establishing how to live with fibromyalgia was an ongoing activity, which routinely brought them back into contact with biomedical practitioners while consulting with a range of complementary and alternative health care practitioners in between (Jackson, 2005). This is not uncommon for people living with chronic conditions, or for those who experience chronic and often inexplicable pain (Mendelson, 2009). For the people involved in this study though, the key determining factors in who was consulted, and which health system they prescribed to, were related to *access, availability and effectiveness.*

The functions of different health care practitioners was also an aspect of the process that meant people with fibromyalgia would see GPs or specialists at different junctures in their illness careers. There were numerous mentions in the narratives of multiple consultations, and in many instances, the participants could not remember who had initially diagnosed them with fibromyalgia. This was because following their diagnosing encounter, which was frequently dissatisfying because the illness could not be explained or addressed effectively through the treatments offered; they often continued to search for relief elsewhere. This is

similar to the patterns of diagnosis reported by Werner et al (2004) and Nettleton et al (2004), where recognition of the symptoms and practitioner competence shape consultation outcomes.

A theme that was carried throughout the narratives was the fact that fibromyalgia appears among other health conditions, and is present on a spectrum where overall health is impacted and needs to be managed continuously. Prof Meyer, in his interview, explained that,

> If people are catastrophising the problem, or ruminating and talking and making it worse and blowing it up, those sort of things also worsen… so we have to look at the cognitive side of things as well. And then there's a lot of other things like treating the peripheral pain generators that I've mentioned, it's important for people to keep on working so we sometimes meet the occupational therapist. There are specific movements that makes it worse, like what we call eccentric exercise where you exercise away from your body or work with the arms extended above the workplace or… do a lot of walking up and down stairs, so there's a lot of things that we have to do adjust that if necessary.

As fibromyalgia retreats into the background of illness experience, through the acceptance of it as a chronic condition and subsequent normalisation, recognising flare-up triggers and symptoms, and knowing the course of action to take in response, becomes a part of everyday life (Richardson et al, 2006a). This does not necessarily mean the condition in its severest state is any less difficult to face, however the absorption of fibromyalgia into the milieu of ordinary existence allows the meaning of the condition to change from that of "crisis" to "manageable chronic illness".

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Adjusting to the demands of the condition, in that fluctuations in energy and pain levels are experienced and often threaten to overwhelm one's capacity and disrupt everyday life, is another task of coping with fibromyalgia. A combination of pharmacological treatments and lifestyle alterations are among the most common of treatment recommendations offered for fibromyalgia (Raff et al, 2014; Whitesman, 2008). Regulating behaviour and sleep patterns as well as managing stress, diet, exercise, and socialising were frequently mentioned by the participants of this study, in the discussions of how they coped with fibromyalgia. These strategies reflect the broader recommendations discussed in the literature (Arnold, 2010). Furthermore, changing work and life routines, and avoiding circumstances and behaviours

that actively affected and often worsened their pain or exhaustion were all tactics utilised by the participants in the course of their illness careers (Sim and Madden, 2008).

Fibromyalgia is a complex condition with diverse manifestations and as such, treatment for the condition needs to be tailored, considerate, and specific to the individual and the location of their experience on the spectrum of severity (Ablin et al, 2012; Butow and Sharpe, 2013; Tutton, 2012). The purpose of addressing fibromyalgia in this way is to accept the chronicity of the condition, and begin the process of normalising the experience into one's life (Jackson, 2005). Sanderson et al (2011: 620) note that "the normalisation of illness is implicit in the biographical reinforcement, continuity and flow concepts… [and] the responsibility for normalisation is implicitly placed on the ill individual or those directly caring for them".

This relates to this study of fibromyalgia in SA because, as found in Prof Meyer's explanation of fibromyalgia and treatment recommendations, there is strong emphasis on accepting the condition, and assimilating the symptoms and treatments into everyday life. As Alison explained in her interview,

> I think it also… it helps to be open about it. Because if you're going to go there and the doctor's going to tell you, "this is what you have…" then you mustn't then be like, "I don't believe you. I'm not accepting it". Then you're just hindering yourself, you know. And also if you're open to experiences and to people and to… you know things that's going on in your life, it'll make a big change. And some people… are rather closed off and they don't want to experience new things, they don't want to meet people, they don't want to accept anything and so on. And it stops you so… I think it helped that I'm also quite open to things… I think stuff like that… and I think that it helps… it helps me.

By identifying the link between "catastrophising" and poor coping ability, Prof Meyer also strongly discourages the perception of the condition as unmanageable, or continually traumatically disruptive. The implication is that where a patient is unable to match the scale of impact of the condition on one's life, they adapt poorly, and cope less readily (Bennett, 2002). If the trauma of diagnosis and the extent of the burden of the condition are blown out of proportion, the patient cannot normalise the condition effectively, and places their

experience in the wrong category. This means that relatively mild symptoms are viewed as catastrophic and hopelessness pervades (Morris et al, 2012). For Meyer and other practitioners in the literature, the effects of vague diagnosis are not as profound, as treatment can often address the symptoms without detailed causal explanations (Morris et al, 2011; Clauw, 2009).

In adopting a holistic modality in treatment approach, insecure explanations do not play as important a role for the practitioner, where symptoms can be alleviated and managed. Meyer (2012) cautioned against the miscategorisation of the experience of fibromyalgia, where relatively mild cases are placed in the same group as people with overwhelming, debilitating versions of the same condition. Part of this involves the individual taking responsibility for realising the chronicity and scale of their condition, their capacity to cope in line with perception and treatment and help available, as well as the effects of social support in shaping the experience (Skuladottir and Halldorsdottir, 2011; Salmon and Hall, 2003).

The difficulty faced in successfully slotting into this process was evident in the narratives collected. In consulting with many practitioners, and being exposed to a variety of approaches, as well as the discrepancies in the availability and accessibility of treatments, people interviewed for this study frequently found it difficult to initially accept their condition, and understand the scale of its impact. Knowing what was causing their symptoms and efficacy in treatment remained primary concerns for the people in this study. This was due to the fact that the experience was continually disruptive and often traumatising, when meaning for the experience could not be found from those they expected to help, such as healthcare practitioners and the participants' families (Glenton, 2003). Both Claire and Connie discussed the lack of support they received from particular family members and the feelings of rejection and distress they experienced as a result. This is explored further in the section that discusses Social Support.

Similar to the challenges faced in naming the symptoms as fibromyalgia and predicting a prognosis of how the condition will play out, treatment for the condition is variable and often requires an amount of experimentation in finding what works and which strategies lead to the

most success in coping with the condition. While there are standardised recommendations of treatments for fibromyalgia, the dissemination of them in general medical practice is disparate and uneven. The experiences related in the narratives collected in the course of this study indicate that the diagnosis of fibromyalgia was far more readily available than treatments that could be used effectively to alleviate symptoms. Many of the participants spoke about the experience of being told what their condition was, but then struggling to find treatments that would work to reduce their symptoms to a manageable state. Their experiences resonate with Bieber et al's (2006) assessment of practitioners who work from curative stances, and the difficulties faced in applying that narrow framework to the case of fibromyalgia, which is marked by multiplicity and complexity.

As Chloe explained, for her, there was a sense that the recommendations only went as far as giving guidelines. Furthermore, in her view, the unpredictable and elusive nature of fibromyalgia made it seem as if "anything and nothing" could work. She said that after learning she had fibromyalgia, her diagnosing practitioner put her on Cyprolex, which she explained was,

> **Chloe:** an anti-anxiety… because I've always been quite an anxious person as well… but…
>
> **SC:** Did it help?
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> **Chloe:** See… in my mind my anxiety is not my problem. It can be a trigger for an episode but so can sitting on the couch watching… a movie. Like, there is no fixed trigger. Whether you do something right or wrong, it can happen. So I didn't want to be pumping myself full of some fairly high doses of these things that gave me mood swings for something that may or may not work, 20% of the time. And… there were a couple of others like that. 'Cause I said "Oh these ones, I don't want, they're not working. I'm just getting mood swings". So we tried a couple more and I just… I got *gatvol.* [12]And I went back for the acupuncture 'cause I was really desperate for anything to work. Then I tried all sorts of Chinese medicines, like "take 8 of these a day". Lots of supplements. Different diets. Oh, he [the diagnosing practitioner] was very big on the diet thing. He gave me this diet that he gives to people to lose weight… And I hardly need to lose weight… And it just didn't work for me. It's the stress of…
>
> **SC:** So what, he was just trying… everything?

[12] Gatvol is an Afrikaans term loosely translated as "fed up"

> **Chloe:** Ja. The stress of trying to keep up with the diet was more than the anti-anxieties…was … um… diminishing… so… it was just retarded, so I decided not to do anything. But that didn't work either, of course (laughter). But nothing does. I think that for me, basically, it's just been a trial and error…

This uneven distribution of knowledge, where a label is available but treatments are unknown, created suspicion of practitioners on the part of the patients. It also prompted a sense that they were not being supported in figuring out their illness and the meaning thereof. Following this, many of the participants of this study turned away from medical practice as their sole source of knowledge, care and help. When symptoms improved and where medical practitioners were part of that process, there was a continuation of interaction with medical services in the individual's management of fibromyalgia.

For the participants of this study, finding a practitioner who was effective in recognising and managing their fibromyalgia indicated a movement away from experiencing "chaos" in relation to their condition. They moved into a space of "quest" where the parameters and responses of their condition could be understood (Frank, 1997). These distinctions are important to note as they explain the help-seeking behaviour of people with fibromyalgia. The narratives collected in this study were able to highlight particularly the isolation experienced by those living with fibromyalgia. This is enforced when they feel abandoned and rejected by those services and people that are meant to assist and support in matters relating to their health (Ong et al, 1995; Stavropoulou, 2011; Thorne et al, 2004).

As Lupton (2003: 95) explains, illness narrative is a means through which patients can begin "to formulate a revised identity and new context for living after the disruption of illness". With chronic illness that has uncertain aetiology and lacks medical legitimacy, such as fibromyalgia, finding support in making sense of the experience is critical. Connie explained,

> For me the most difficult [thing] was you have to cope with it yourself. You don't even understand what it is, what's going on and then people around you, you know, they don't know what you're going through so they don't know how to support you or they don't realise that you need support. And in, you know, some cases, some days, they either make it out as

> you are putting it on or, you know, you're too stressed out and, you know, you're depressed or something like that. That made me really angry and then other doctors would just, once you get to them, eventually they'll just take blood and send you for x-rays. You come back, clean, and they tell you "I don't know what's wrong with you" but you can't walk or you can't use your arm or something like that.

While this is a common experience for those who live with chronic illness, the lack of recognition for fibromyalgia in broader society contributes significantly to the sense of isolation and disorientation that Connie describes above. In trying to construct a narrative and draw meaning from those around her to explain what is happening to her, she hits obstacles in the form of scepticism and active de-legitimisation, both from those in her social circle, and in the failing of biomedicine to categorise her symptoms.

Treatment recommendations

Prof Meyer explained, in his interview, that physical activity played a critical role in the treatment of fibromyalgia, as it led to vastly improved symptom experience. He elaborated and detailed other recommended treatments that are dispensed in SA medical practice by saying that,

> Ja, that's the key. I would say, you know, in general terms. Obviously you have to improve the symptoms so we use different drugs for that. There's currently 3 FDA-approved drugs, 2 of them in SA. One is Duloxitine or Cymbalta, the other one is Lyrica. We also use the older generation of tri-cyclic anti-depressants for sleep and for pain. And then we use analgesics like Tramadol and Paracetemol. All of those things improve symptoms, but the bottom line is that you have to improve function as well, that's why exercise is important.

In his explanation, Prof Meyer highlighted many of the components of fibromyalgia, and particularly what makes it such a complex condition to identify, treat, and manage. On the physical level, there is obvious discomfort and distress when experiencing inexplicable and overwhelming pain and exhaustion.

This is compounded by the barely visible and intractable nature of the pain source, in that systemic pain processing is challenging to treat correctly. In confronting the condition of

fibromyalgia, there is a need for a holistic approach that tackles many, rather than specific, aspects of the illness experience. A multi-level approach to treatment is needed, in noting the link between physical movement, neurological abnormalities, personal and cognitive factors (Houdenhove and Luyten, 2008). Furthermore, addressing the overlap with other central system sensitivity conditions (such as IBS and migraines), and mood disorders (such as depression and anxiety) is important when developing a treatment programme for fibromyalgia. As Prof Meyer explained,

> So 20 years ago, to come back to your initial question, we thought it was a discrete illness. And that was fibromyalgia, widespread pain in 18 tender-points. Today we know it's part of a spectrum. So it runs with what I've already indicated plus irritable bowel syndrome, tension type headache, migraine… so there's a number of disorders we cluster together. What we call the central pain disorders. With a strong genetic underpinning. And in that very same genetic underpinning you also find a predisposition to some of the mood disorders like anxiety, depression, but... related with that. So that's more or less how we see it and how we treat it in an active way, participating… management, doing the exercises, your stretches, using the correct medication, treating peripheral pain generators when they are there… and I think it's very important, the cognitive restructuring because your anti-pain modulating pathways also connected to the way you think. So that in a nutshell is how we do it, ja.

Prof Meyer was also advocating strongly for patient participation and education in managing fibromyalgia, in that the responsibility for care was a collaborative effort between the patient and the practitioner. This corroborates with the approach presented by Arnold (2010: 397) where, alongside pharmacological interventions, there should be the "integration of psychoeducational approaches, including education about the disorder, support groups, and CBT, [which could] be helpful in improving patients' ability to cope with FM". Recognising and treating the multiplicity of fibromyalgia is a critical route that leads to reduced symptom experience and improved health, where fibromyalgia is no longer a limiting, unmanageable condition. Rather, it is transformed into a chronic condition that an individual can manage themselves, when they have the appropriate knowledge and sufficient access to recognising practitioners, assistive treatments, and a supportive social network.

The concept of 'shifting normalities' is applicable here as there is similarity in the issues

surrounding treatment for those with RA and fibromyalgia (Sanderson et al, 2011). Specifically people with RA, like people with fibromyalgia, can move "between different typologies of normality depending on changing severity of symptoms, efficacy of treatment, ability to adjust to illness, or the influence of contextual factors" (Sanderson et al, 2011: 630). This indicates the fact that normalising conditions like fibromyalgia and RA is a continual process, affected by many aspects of the illness experience that pose challenges to the expectations, trajectories, and outcomes of treating these conditions, and require holistic approaches when addressing the symptoms.

Adapting to fibromyalgia and finding "what works"

Some of the participants felt sceptical about their diagnosing and other practitioners. They were reluctant to continue interacting with the medical fraternity once they had a label and a general explanation for their symptoms. In other cases, there were instances detailed in the narratives where immediate health crises, like needing an appendix removed, overwhelmed the presence of fibromyalgia in the individual's health schema. In this scenario, the same practitioner who had diagnosed and was treating the person for their fibromyalgia was consulted. However, as this was an acute episode of serious illness, rather than a continued management of an ongoing chronic condition, the treatment recommendations and trajectories were very different.

At the time of her diagnosis, Alison had been working in a job that led to irregular sleep patterns and this, along with poor diet and mild depression, had brought on the symptoms of fibromyalgia and caused her to seek a diagnosis that could explain what she was experiencing. This was similar to the experiences of Zainab, who was mostly managing her fibromyalgia successfully, and Kate who had recovered entirely from her encounter with the condition. Zainab explained her approach to addressing fibromyalgia, in relating the advice she had given to a newly-diagnosed friend. She said that,

> I've got a friend who's says… well she's been… also doing, for many, many years, always something wrong with her and… so now they finally told her also, she's got fibromyalgia… and I said, you know… what I… advise is… really take control, nobody's going to do it for you…

> 'cause that's what I've basically been telling people… well with… you know, well whoever seems to have this… even some people who are not diagnosed with fibromyalgia but they've been going up and down to the doctor with you know, chronic pains and nobody can diagnose them and I've just said… see what works for you… you know… diet, exercise, that kind of thing… but don't just stick to the doctor and try and stay away from the drugs if you can…

Having awareness of "what works" for her, and offering advice and recommendations to her friend also indicates the particular stage that Zainab is in within her illness career. Knowing that she is control of her symptoms, that they are chronic, and manageable has empowered Zainab to lend support to her peer, as she draws on quest narratives to explain her experiences and treatment strategies (Nettleton, 2006b; Issner et al, 2012). Kate, who had experienced severe symptoms for two years before they subsided after her diagnosis 10 year ago, was also knowledgeable about which lifestyle changes had impacted her illness the most.

In this passage, she also highlights that her information was sought online. Searching for knowledge and clarity of the meanings and responses to fibromyalgia was a common practice among these study participants, and shows the variety of information that circulates in the illness careers of those living with the condition (Audulv et al, 2012; Nettleton et al, 2004). Kate explained that adaptability was

> the key and I can tell you exactly what it is. It's your acid levels, no red meat, no alcohol. I didn't drink alcohol for a year; I thought I was going to die. Thank goodness I'm drinking again. So you've got to completely cleanse yourself - this is from the thing I read online. Cleanse the system free - walking, no alcohol, no red meat… Vegetables water - like rid your whole system. Then I also read this thing about your liver, that if your liver - no it isn't your liver, what's your other one? Your kidneys and your liver. So basically I read this thing about if you cleanse a lot of the dirt and the muck gets held there so if you keep that cleansed then you'll be fine. Like it was a backup in your system that obviously poisons your whole body. That's what I read at the time, so who knows but I stuck with that.

In her diary, Alison wrote about the fact that she was still sceptical of fibromyalgia because it

lacked explanatory clarity, but she acknowledged that both the labelling of the inexplicable pain and the subsequent treatments she had used had led to improvements in her health that she couldn't question. She described the types of pain she experiences and the effects thereof, before explaining what routes she follows to remedy this. Alison detailed in her diary that,

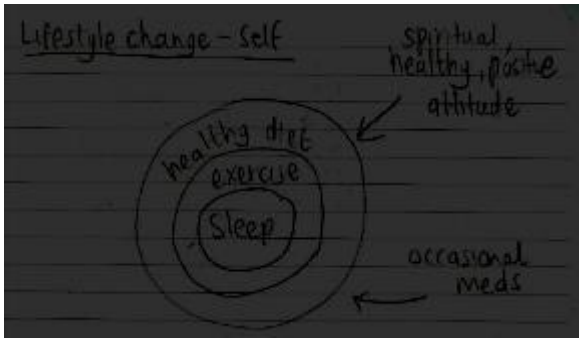
> My areas of pain when I have an attack are: back, knees, shoulders, hips and neck. I feel like I am about 90 in the shade when I am affected. It gets to a point where if I sit cross-legged for more than 5 minutes it is painful to unfold my legs and have to it very slowly.
>
> Things that tend to my FM worse are when I am ill like I have explained, particularly flu; when I am very stressed like when I am writing exams or have many dead-lines looming as well as when I have my period (personal, I know) but it is because my entire lower body aches like hell when I have my period, causing my lower back, hips and knees to ache like I have arthritis.
>
> Dr Thomas [GP and diagnosing practitioner] recently told me I could possibly develop an autoimmune disease looking at my medical history and that I need to keep an eye on that. I know that there is a possible link between FM and autoimmune diseases which just cements the fact that I definitely have FM.
>
> The current "side effects" I have from FM are migraines- at least once a week; and IBS… both [of] which really increase the pain when I have my period too! I have sinusitis too, chronic sinusitis which I am not sure if it has anything [to do] with FM but thought I should mention it.

In the above passage, Alison concisely describes both the complexity and multiplicity inherent in fibromyalgia experience. She lives with many chronic conditions alongside her fibromyalgia; conditions she notes are both caused by and exacerbate her fibromyalgia. The linkages she makes between the different forms of pain she experiences on a regular basis allow her to bolster her identity as a person with fibromyalgia. Alison, in her narrative, reflects what Sanderson et al (2011: 626) describe as "resetting normality", which requires "a conscious reconceptualisation of a normal life as incorporating the illness, fluctuating symptoms, and a changed body and self". Alison attempted to manage her condition by changing the parameters of her expectations of capacity and health, in order to account for her range of illnesses, and the effect of her fibromyalgia particularly on her capacity and experience of wellbeing.

She displays the scepticism she feels around her diagnosis, the amount of knowledge she has of the condition, and the causal explanations attributed to giving the condition legitimacy. This is done as she makes the connection between potentially having an autoimmune condition in the future, and the acknowledgement that having fibromyalgia predisposes her to this. For Alison, treatment of fibromyalgia was a process that encompassed many aspects of her wellbeing. In her diary she included the following explanation and diagram:

> How I am currently treating my FM - with as little medication as possible because I refuse to become reliant on pain meds, but if it is bad, I will take something instead of suffering but it is more of a last resort because in my opinion, it can be treated without meds. That is also my doctor's opinion too.
>
> I try to constantly exercise, especially cardio where my heart rate increases and my body gets warm and also more relaxed, meditative exercise like yoga to calm my body and mind. I have joined a movement called Crossfit (Crossfitjozi.co.za) that is so fantastic and I have not felt my FM in about 2 months just from the constant exercise 3 times a week.
>
> Also, I am trying to eat a healthy diet where I eat a lot of veg and protein and monitor my carb and fat intake. Don't get me wrong, you need all foods to be healthy. I am currently following the "Zone" diet which can be difficult at times but my body is telling me that it is working and I just feel so much healthier and energetic!
>
> My better sleeping patterns have definitely contributed to my reduced FM symptoms. I hope to eventually be without the Melatonin tablets when my body starts producing it itself.
>
> The last and most important aspect is to have a healthy, positive attitude towards having FM. Yes, it is a terrible condition that is crippling for many and it seems like it is so far away to become positive about it. I had a terrible time with FM but it's not going away. Acceptance is the first step. Second step is not letting it affect what you want to do. Don't let it control your life. The choices about it are in your hands. You decide just how much you want FM in your life.
>
> The biggest thing to realise is that FM is in your life. So now, you need to make a lifestyle change in order to steadily beat it into submission! You can do each of these separately, but the only way you will see + feel real results is if you do all of them. You have got to adapt now that GM has come into your life. You were strong before and you will be strong again.
>
> Ha! I sound like I'm preaching! The only reason I am saying this is because it is working for me. It is a constant thing, it not a once-off treatment and done! FM is gone. No, it will never be

like that. It is a complete and total commitment to changing yourself and your life.



In her description, Alison effectively captures many of the aspects needed to address fibromyalgia through treatment (Arnold, 2010). A combination of lifestyle factors, regulating sleep patterns and diet, as well as doing exercise, and taking appropriate medications all contributed to an increased sense of wellbeing for Alison, and a reduction in the frequency and severity of her fibromyalgia symptoms. Alison reflected on the important role of acceptance and positivity in approaching fibromyalgia, and in realising the chronicity of the condition, she was able to adapt her life to accommodate the condition to the point where she was successfully managing it and coping relatively well (Jackson, 2005: Morris et al, 2011). In "resetting" the normality of her conditions, and adapting to the chronicity of the illnesses she experiences, Alison effectively has shifted what her expectations of health constitute, and modified her experience through accommodating the condition as an impacting, but manageable condition (Sanderson et al, 2011).

Taking a holistic approach to her health generally, and attempting to find balance between physical, spiritual and emotional wellbeing worked for Alison. The peak of pain and exhaustion is felt during the worst phase of fibromyalgia, where symptoms are frequently overwhelming, and relief through treatments is not readily found. Having found strategies that allowed Alison to gain distance from this experience, she was able to identify the factors, practices, and remedies that were effective in allowing her to live a healthier life, where pain and exhaustion did not dominate her existence in the way they once had.

The recognising attitude she encountered with her healthcare practitioner, and the support

provided in bringing Alison to a place of understanding the scope and impact of fibromyalgia on her life, meant that overcoming the experience became something that was possible and achievable (Werner et al, 2003). Her healthcare practitioner played an integral role in allowing Alison to move through the process of "resetting normality". At this stage of the interview and diary process, Alison was able to articulate her experience in a way that expressed her understanding and grasp of the condition and its mechanisms. Importantly, Alison identifies the tandem process of eating well, exercising appropriately, and regulating sleep patterns and lifestyle routines in ways that support her in coping with her condition. In realising the meaning and placement of her symptoms in the schema of her fibromyalgia, she is able to take a lateral approach to tackling her health by seeing the triggers and responses that lead to changes in her wellbeing. In noting the relationships between different aspects of her pain and illnesses, such as migraines and IBS and sinusitis, and the way they are underscored by her fibromyalgia, Alison also understands her conditions as interconnected and part of a spectrum.

In this process, Alison is embodying what Sanderson et al (2011: 626), citing Locock et al (2009) and Schwartz et al (2004), explain as biographical repair and response shifts. In this, the sense of normality in altered life caused by illness is achieved through the restoration of meaning and adaptation to changed circumstances, as well as the new expectations of self and capacity and understandings of being "healthy". This was demonstrated in Shreela's discussion of her treatment regime,

> **Shreela:** Um… what I learned from Teitelbaum[13]… is that it's very important to do body-energy balancing work and um… part of that is yoga and the other part of it is acupuncture and acupuncture works very well for me in the sense that it helps me sleep deeper. And it just, it's like meditation you know. It kind of just gets me… completely settled and calm and grounded. So…
>
> **SC:** And you've been experiencing pain not regularly? I mean what is the change in comparison with the story you've got here of… how severe it sounded at the time of you going to see that doctor?
>
> **Shreela:** About 5 percent of the pain that I had then and… only when… uh, when I'm in… when I'm under stress and then… and very mild. And all I do then is I rest. I rest and then…

[13] A book Shreela used extensively in her management of fibromyalgia

SC: And that works?

Shreela: That works and I might take just an extra dose of Lyrica. 'cause the Lyrica is mainly for the pain.

SC: And the fatigue?

Shreela: Oh Lyrica is actually mainly for the pain and the fatigue. Um… and uh because the fatigue is so intricately linked with the sleep patterns… the… the Zopiclone sorts that out.

Shreela had discovered techniques and strategies, as well as information, explanations and treatments that effectively alleviated her symptoms, and allowed her to manage her fibromyalgia successfully. Identifying the components of the condition, and developing responses that worked, with the assistance of practitioners, self-care tactics, medications and routines, all ensured that Shreela was able to mostly recover from her fibromyalgia (Ablin et al, 2012).

Treatment adherence

Alison, Kate and Zainab's narratives were distinct from others in the interview cohort who were coping less well, or dealing with more severe symptoms, and therefore unable to stand aside from their illness, and reflect on it in the way that Alison related in her diary. The multiplicity in manifestation of fibromyalgia is what produces the diversity in narrative found through the study conducted. While all participants were able to be reflective about their experiences with fibromyalgia, only a few of them could be reflexive, and identify coherent strategies used in coping with and managing their condition. Those who had found treatments that successfully reduced the severity and frequency of their symptoms were able to move through the worst of the condition.

In this place, adaptations and alterations to living with fibromyalgia could be made. These experiences constituted quest narratives, as the focus of their illness career was around managing the chronic condition, rather than attempting to overcome it (Whitehead, 2006). In

cases where the severest state of the symptoms were still being overwhelmingly experienced on a frequent basis, the space needed to be reflexive, and the ability to see a pattern and find responses, were simply not available. These participants' narratives were characteristically "chaotic" in nature, as the anchors of responses and reactions gave no clarity to the trajectory of their illness experiences (Nettleton et al, 2004).

Seeking alleviation became the primary occupation of those living with fibromyalgia, once the diagnosis had been dispensed. In many of the narratives, the process of learning to live with the condition was an undertaking that played out over a long period of time. It was also fraught with complications, and pinning down the patterns of what effectively worked was an arduous task (Aalbers, 2012). Additionally, because of the intractable links between fibromyalgia and their behaviours and lifestyles, many of the recommendations offered by practitioners to the patients were ineffective, because they could not be achieved (Werner and Malterud, 2005; Audulv et al, 2012; Butow and Sharpe, 2013). What this means, for instance, is that if changes to lifestyle needed to be made in order to address fibromyalgia, and work routines needed to be slowed down to accommodate the condition and its demands, there also needed to be financial security for the person to continue their lives without working as much. If the individual was a breadwinner for their family, then aside from personal fulfilment and a desire to work, there simply was no way that this recommendation of working less could be adhered to, when they and other family members were relying on their income.

The immediate task of finding treatment that worked, routines that were manageable, and support that was assistive, was often a process undertaken with urgency. It was often marred by the undercutting and damaging delegitimation and unpredictability discussed in earlier chapters of this thesis. Claire, who ultimately consulted with Prof Meyer about her fibromyalgia treatment, captured this complexity in the following description she offered in her interview,

> **Claire:** I think… what's quite… it… the point of obtaining the diagnosis and then… going through enormous personal stress of… divorce, selling houses, moving, children, kids… incurring quite serious injuries during that year… I think that… that all… kind of meant that… what seemed quite strange was that as it was… as I was heading into… well from diagnosis

into treatment is… it was actually getting, the symptoms were getting worse… but I think.. what helps is… the framework and the understanding.

SC: So… figuring what's going on

Claire: That the meaning-making… thing… and I mean I must say, since being with Prof Meyer and with the… the treatment… the symptoms are not as… as serious and… the despair… you know, like when it's happening, I can put it into perspective and I can say, "ok, I'm in a flare-up, it's going to last for two weeks, I've been here before, you just have to now cope from day to day and then you'll be back"… I'm closer to being able to believe what I tell myself.

For Claire, the process of diagnosis brought a means of understanding her experience, so that it could be contextualised and given meaning. She was able to begin the process of resetting normality, as she experienced what Sanderson (2011: 626) described as "a healing of self-identity, from feeling reduced to being a patient post-diagnosis, to becoming a person again". While her symptoms worsened in the course of the process, she eventually was able to recognise the onset of a "flare-up", and could respond appropriately by altering her daily life to accommodate the experience and cope with it. In her diary Claire described the iatrogenic effects that her medications were having, and the clarity that this brought to her experience of fibromyalgia and how to handle it. She wrote that,

> It has been quite a bonus to work this out, but also a reminder that chemicals are not a silver bullet, and that one needs to remain vigilant and critical of the solutions that one seeks for the problem. What has happened is that I have been thinking carefully about the meds that I am on after having weaned off the sleeping tablets and seeing that Wellbeutrin* causes more trouble than it is worth. Since seriously considering the diagnosis of fibromyalgia I have used Lyrica since it is some kind of gold standard in the treatment of neuropathic pain. As an added benefit it has also just been registered a treatment for anxiety by the American FDA so it has always made sense that as a chronic pain sufferer with tendencies towards anxiety that I take Lyrica. My initial experience of it was that it made a huge difference at 75mg, but that any additional morning doses to increase the total daily dose made me too tired to function. At this point I should have noticed that I am sensitive to this chemical because this is the absolute minimum of a therapeutic dose (an uncommon experience for me). For two years I have taken Lyrica, and with each month it has felt like the headaches have become more debilitating. I never made the connection. At the point of making this observation, and in

> keeping with my motivation to rationalise my medication I remembered that Neurontin had a stimulating effect on me, and given that it is also used to treat neuropathic pain I thought that I could wean off the Lyrica and replace it with Neurontin in the hope that I could then get off the Ritalin.

Claire's profession affords her the privilege of being in constant contact with healthcare practitioners. As a psychologist, she had access to knowledge that many of the other participants in this study lacked about the mechanisms of fibromyalgia and neuropathic pain, as well as the means of treating it. In the diary entry, Claire displayed the strategic use of medication she employs in treating her fibromyalgia, as well as the connectedness of her symptoms, and the iatrogenic effects that coexisted with the benefits offered by the medications she was taking. She employs agency and self-care in determining what effects her medications are having on her wellbeing, and whether she will continue with particular treatments (Audulv et al, 2012). She related that,

> To my surprise weaning off the Lyrica was seamless and easy process, and what I quickly saw is that I was having pain free days with my headaches. It has completely changed my day to day experience of the pain, and now I have days where I don't have to take pain meds. It feels like a small victory… but one that holds a lesson worth remembering. Some solutions are problems in and of themselves.
>
> I have decided not to use Neurontin because I am feeling very cautious about the potential side effects of meds.

Anxiety and headaches are common comorbidities associated with fibromyalgia. Recognising that a recommended treatment could be exacerbating the experience of additional conditions, while simultaneously providing relief, is important to note when addressing treatment for chronic pain conditions like fibromyalgia (Raff et al, 2014; Ax et al, 2001). Claire's turn away from Lyrica (the "gold standard" of fibromyalgia treatment) and Wellbeutrin came after she found her symptoms to be worsening, where the expectation was that they would improve. In moving towards self-care through the experiment she conducted of weaning herself off her medications, Claire was able to discover both which treatments were assistive, as well as gaining a deeper understanding of the nature of her conditions (Gately et al, 2007).

In the initial interview held with Claire, she spoke of the difficulty of "getting ahead of the curve", where symptoms were constantly overwhelming and ungraspable, which in turn made it difficult to figure out strategies and responses. Finding alleviation from some symptoms, through the use of effective treatments, allowed Claire to pass through that phase, and into a space of reflection where the locations, contexts, and causes of various aspects of her conditions could be viewed with clarity. Additionally, recognising and contextualising her experience through the legitimacy and explanation offered by the diagnosis of fibromyalgia enabled her to begin forming routes of response. This in turn afforded her opportunities to accommodate fibromyalgia into her life.

Shreela, who had previously used alternative treatments in addressing her health issues, described the process of coming to the treatment regime she was currently using. She had largely recovered from her fibromyalgia, and was enjoying good health at the point of our interview. She described both the severity of the symptoms, and the important contextual factors that brought her to the point of seeking help from a psychologist she had previously consulted with. She stated that,

> Currently I'm in very good health and um… so I'm currently in good health. Um. In far better health than I was at the beginning of 2009. And part of the reason why I'm in good health is because I shifted, at the end of 2009, the beginning on 2010 actually… I shifted from Chinese herbs to conventional medicine. And um… I… at the beginning of 2009 I was just… I was still on Chinese herbs and I was exploring… because I was still achy. I mean I lived with pain for 11 years. And… um… at the end of 2009 I went into a deep abyss and a very close, my closest friend who is also a psychologist… she said to me "if you don't go on conventional medicine, you're not going to get on your plane to the US". Because I was due to go to Harvard at the end January and from the beginning of November… so I took her advice and went to see my… psychologist. Very experienced… And um… so I went back after my friend said to me, "if you don't go on conventional medicine, that's it". And he then put me on… um… Zoloft, Zopiclone… which is… Zoloft is a… he actually… recommends Zoloft for fibromyalgia… it is an anti-depressant but the most important thing for FMS-ers is that it is anti-pain and it helps with sleep. Because from what I learned from the research that I did, is that FMS is primarily a sleep disorder. And then I was on Zopiclone. I still am on Zopiclone, you know one every night… for sleeping. And… uh… Lyrica. Which is supposedly the

> important medicine for FMS-ers. And the good news is that I started off on 75 milligrams of Lyrica a day. So I would take one in the morning, one at lunch, one in the evening… and I'm now down to one a day which is 25 milligrams.

In this, Shreela experienced what Sanderson et al (2011: 627) refer to as "returning to normality", where normal life was reasserted and symptoms were not noticeable. This was signalled by effective treatments and positive responses, as well as a "return to 'feeling normal' and a 'normal life' [which] was linked to perceptions of having regained a healthy body and identity" (Sanderson et al, 2011: 628). Shreela explained that her new sense of wellbeing was noticeable in how able she was to live without the worry of fatigue. She said,

> I have zest for life. I have… a sense of vitality. You know, I sleep well. I can… do… I can function from 9 to 5, you know, without, um… having a dip either in the morning, or in the afternoon. Without needing to just go home and rest. So um… I eat well which is very important. I have… I'm not a big socialite, you know, but I have a bit of social life which I think is very important, because when I was living with pain, you know, it was - and fatigue, it was very hard… to… um… to kind of go out and be with a whole lot of people or even be with 4 people because… if I didn't feel well in the middle of it all, you know you feel like a bit of a party pooper. So um… ja… so I have a… for someone who's an introvert I have… a reasonable social life.

The simultaneous process of continued symptoms, a supportive network of peers, and a recognising practitioner that could recommend appropriate and effective treatment all led Shreela to a regime of medication that brought manageability to her illness experience. This augments Werner et al's (2003) notion of a "recognizing attitude" as the impact of validity, acknowledgement, and support all positively shaped Shreela's experience, and enabled her to effectively manage her symptoms. Shreela used a variety of treatments, but she attributed the improvement experienced in her health with regards to her fibromyalgia directly to her encounter with the psychologist and the move to biomedical treatments. She was able to get her sleeping patterns regulated, and through strict diet and exercise, she had seen a consistent improvement in her symptoms. This meant that she could identify the factors, scenarios and outcomes that could be expected and accommodated as she continued to live with fibromyalgia (Meyer, 2006, Ablin et al, 2012).

There was reluctance and suspicion found in the narratives with regards to a variety of treatments. This is an illustration of Shiri et al's (2007: 353) explanation of the health belief model, which states that "factors such as cultural norms and knowledge about a disease modify beliefs and perceptions and can thereby influence behaviour, for example, adherence to therapy". The strongest resistance was expressed around the recommendation of anti-depressants in treating fibromyalgia. However, there was also a sense that if a treatment was helpful, and reduced the severity of their symptoms to a manageable state, then it would be used regardless of which sector or health system it belonged to. Kate succinctly explains her approach to treatment, and the importance of dispelling the stigma that surrounds psychological conditions and medications (Cohen et al, 2011). She said that,

Kate: Ja, but in terms of a long term you can try and do whatever you need to, to get right.

SC: It's not an easy question I know. It's not clear-cut either. Some people would feel like it's something that's in them that's wrong and that's why they're feeling ill at that point.

Kate: That's back to that whole mental thing, if you're down and depressed then you fall into I suppose.

SC: True. And you accept that way of being rather than trying to change and get away from it?

Kate: Yes, so take an antidepressant and get over yourself. And they must all be on antidepressants, I'm telling you. Because the physical puts you down and you to flick that around and you need something to flip that around. You've gotta be crazy - you need antidepressants to switch your mind set. You need support, you're not gonna be superman and jump out of it in a spandex suit. They must all be on antidepressants. They must all get on there out of that depressing state.

SC: So it actually can be just as much that you're experiencing physical pain that you're not in the right state of mind to deal with...

Kate: I think so. It's that whole thing where they say if you're depressed then you can slip into this, and you get this and get that, but I also believe that if you are in pain or something goes wrong for example that you go into it - into depression. Get on those anti-depressants, go to the doctor and say "I'm depressed". Maybe I was depressed but I think it went the other way round for me. I think you've got a natural depression state. You know everyone is a bit depressed

about something - that's life. Maybe my physical, my physical well being obviously that pushes you back into it. If you were really depressed that wouldn't stimulate you...

SC: Sure, so it could be a two way street.

Kate: Definitely. And I think for a lot of people it's probably the physical pushing you into depression.

SC: Sure. So maybe if you deal with depression it would largely deal with.

Kate: Yes. You're depressed so take a sleeping tablet, go for a walk, stop doing this and that and do it. I don't know why but people also have a block against anti-depressants because they think that it's a… but when your physical state is completely messed up I say take them. Do it. 'Cause it works.

In tailoring treatment regimes to themselves, the participants in this study had to become aware and articulate of how the medications were affecting them, They additionally had to be cautious about the extent to which the side effects of the medications were tolerable. Distinguishing between conditions and pain sources, and which treatments appropriately addressed them, was an arduous task for the people interviewed in this study. Some recommendations were difficult to adhere to, like exercising or resting (Butow and Sharpe, 2013). The former was tricky as there was concern expressed about the chance of overexerting oneself, and therefore experiencing pain or lacking energy. This meant that finding motivation and ability to exercise was challenging. The latter was counter-intuitive for many participants who experienced exhaustion as overwhelming, and so when they had energy, the idea of resting did not sit well.

For Connie, the advice given that she should rest stood in conflict with her desire and nature to be a busy person. She found a lot of fulfilment in her work, and was aware she stretched her limits often. She stated in her interview that,

I'm a workaholic. I'm sorry to say it, I won't say it in front of my husband, but I'm a workaholic and I'm pushing myself, like today. I'm normally, let me just tell you, I usually go to the doctor like today, get my injections, get into the car go to the office. Work until 5, half past five and come back 'cause the injections keep me awake. So for me it serves no purpose to be at home,

it's frustrating because I'm looking at the ceiling. I'm stuck to my hot water bottle for the past three years. Permanently. Even through these heat waves, every night. I've got my hot water bottle. My hot water bottle, my medication, healthy lifestyle, exercise, I'm walking every night I'm taking a very far walk.

For Claire, the vagueness of the aetiology of fibromyalgia posed challenges for her in following the recommendation of "living within limitations", and especially in terms of resting. This is reflected the findings of Miles et al's (2005) study of managing constraint. She also dealt with much derision from her ex-husband, which contributed to her sense of scepticism around the need to rest in order to manage her condition (Issner et al, 2012). She shows that, despite her new partner being supportive and understanding of the demands of her condition, she struggled to overcome the stigma she had previously faced (Jutel and Nettleton, 2011). For her, enacting the behaviours and practices associated with the treatment of fibromyalgia also involved behaving in ways that those surrounding her viewed as laziness. As she explained in her interview,

Claire: … I think because there isn't like a germ… or a… like some kind of cellular process like, abnormal cells for cancer or… it still feels like it's hard to… oh there's something else that actually came up which relates to this… is… it feels hard to kind of… you know… just accept it as like… like an illness. And even talking about it as like not feeling well… it… it kind of feels like, well maybe it is just tiredness, maybe… I think I personally struggle with… this idea of… needing to rest. I don't like it. And it feels like, I always think that other people are very judgemental around the needing to rest. Like I mean I don't think my family understand it. Like in terms of my mother and my father. My ex-husband used to say things like, "ag, you're just flipping tired all the time, you just need to get yourself together

SC: But why do you think that? I mean from him. I can see where your logic is with your family and with your ex-husband… but with him?

Claire: I think it's just hard to think that somebody would bring something different into the equation… that other people would relate to it differently…

SC: Because overwhelmingly your experience has been of not being accepted.

Claire: Mmm… people just being very critical of like… you know… "just like get yourself together"… you know… "like you can't be tired"… um… "you can't be in pain". You know, pain's just… "you're just taking pain killers almost, like, you know, you're taking that strong

> pain killer for like a small pain that you could ignore". Um… and I think that that's been… kind of largely how it's come across to me. And it's hard to think that other people would… would relate differently.

Michelle also described the difficult found in knowing whether it was definitely fibromyalgia that was causing exhaustion, especially having largely recovered and moved on from the apex of overwhelming experiences of the condition. She struggled to identify the concrete links between her exhaustion, her migraines, and her fibromyalgia. This was additionally challenging, as she had not particularly accepted that she had fibromyalgia, because her symptoms could be described through other conditions that she had experienced for longer (Glenton, 2003). Michelle explained that,

> It's difficult to… I think I am more in touch with my body and my body feeling pain and tired than I used to be and I… so I do… there are times where I just feel I just can't, I just can't do anything. And then I don't and I don't think of it as, this is fibro. I sometimes just think, oh well, I'm really tired. Or I'm really exhausted. I'm sleeping a lot less now than I used to but I've had periods again with the fibro, I've had periods where I've battled to sleep and I don't know if that's linked to the fibro or just going through different phases but at the moment I'm sleeping pretty well. But the times where I can't sleep I eventually take sleeping pills 'cause it'll go for sometimes night after night after night where I'm struggling to sleep or I fall asleep, I'll wake up at two and I can't go to sleep again. Ja.
>
> But I think it's also… how much of that is fibro or linked to migraines… the division between them is very difficult. 'cause I'm not migrainey all the time. Um… and again the… what's the relationship between stress and migraines and fibro… because… I would have said that for me my migraines, if I look at migraines over my life, have been very much related to my cycle. Um… and not to stress. But then I have had episodes of things that have been very related to stress and I can tell this is what it is. Um…. But interestingly in the Netherlands, they've done research where… this guy actually won an award and got a sum of money to go and do further research where he said… migraines cause stress. Not that it's always stress causing migraines. And it's funny because um… with me when I look at the times where I've had migraines and pain and all the rest happening together, I am very stressed and it doesn't mean… I'm like stressed where it isn't because something majors happened or whatever; I'm suddenly stressed about silly little daily things. And again its part of that kind of flare up. The stress goes together with the migrainey feeling with the feeling of not being able to tolerate smells and so on… irritability, feeling exhausted, feeling pain and so on, it's like all in a big ball. And I must say

> when I'm like that I'm not in a good way. And I don't term myself sick. I term myself, I say I'm out of sorts or I say I'm… I mean I remember telling one boyfriend of mine, "please, you know, when I get like that, please know I'm not well and I'm not myself, I'm not me. Don't argue with me. I can be irritable, irrational and all those things but it's not the real me". It's me in a particular state. Flared up state or whatever.

Identifying both the causes of illness, and the responses that are effective in addressing fibromyalgia, and bringing to a manageable chronic condition is a challenging task (Richardson, 2006a). Having discussed some of these challenges and the recommendations offered to the participants of my study, the next chapter will discuss the role of institutional response and bureaucracy in the experience of fibromyalgia in SA. Additionally, the necessity of supportive social networks, and the important contribution made by various knowledge sources to coping with fibromyalgia will be discussed.

Institutional Interactions

This chapter will discuss the impact of various institutional interactions on the experience of fibromyalgia in the SA context. The evidence gathered in the course of the research process has indicated that the legitimacy of fibromyalgia as a diagnosis continues to shape the ability of those living with the condition to adapt and accommodate the experience into their daily lives. The key aspects of interaction that are affected by the insecure credibility of fibromyalgia, and the unpredictable prognosis and treatment effects that are attached to the condition, include doctor-patient encounters, workplace attendance and accommodation, and healthcare service utilisation. Additionally, the operational mechanisms of medical aid schemes in SA, and the consequences for people living with fibromyalgia where access to healthcare is limited by the low status of the condition on the medical hierarchy of diagnosis, will be analysed in this chapter.

Crooks et al (2008) explained the effect of contested conditions on institutional interactions, where legitimation and entry into sanctioned sick roles is determined by specific categorisations of illness as severe, chronic, disabling or enduring. This explanation is relevant for the discussion undertaken here. The evidence analysed below will show the paramount role played by the interactions patients have with their practitioners, their workplaces, their families and peers, and finally the medical aids used in the SA context. These interactions can be seen to influence particular attitudes, behaviours, knowledges, and practices that characterise the experience of fibromyalgia in SA, particularly after the point of diagnosis. Showing the complexity of the experience, and the various actors and institutions that shape the process was a key contribution made by this research.

It is a challenging illness experience, and in trying to capture different levels of interaction (many of which occur simultaneously), it is apparent that the extent and type of support found from each of the institutions mentioned above will have an impact on those living with fibromyalgia. These interactions either facilitate or inhibit their recovery and ability to cope with the condition. The disparities in experience found in the cohort of people interviewed for this study can be explained by the individuality that is distinctive of fibromyalgia, as well as

the uneven distribution of knowledge and practice found across biomedicine. In attempting to fit a condition characterised by flexibility and unpredictability into an inflexible social institution and structure, further chasms form between the expectation and the experience of interacting with biomedicine in addressing fibromyalgia and other contested illnesses (Lupton, 2003; Dumit, 2006; Timmermans and Almeling, 2009; Arnold, 2010).

Critically, the amount of flexibility required to tackle and absorb fibromyalgia as a chronic condition presents challenges to the rigid structure of medical categorisation, which reduces the ability of practitioners, management structures in workplaces, and medical aids, to effectively address the illness (Mik-Meyer and Obling, 2012). This is due to the fact that all those institutions operate in a relatively inflexible manner, where prediction and uniformity are preferred in order to offer responses. Fibromyalgia as a condition is characterised by heterogeneity, and the manifestations of the illness vary from person to person (Meyer, 2006).

Formulating responses that adequately account for the diversity in experience, as well as enable people with the condition to effectively cope with and manage their fibromyalgia, is a challenging task, particularly within rigid bureaucratic structures. While there was a fairly high level of consistency found in the descriptions of the diagnosis process presented by the participants of this study, in the case of viewing how people living with fibromyalgia adapted to the demands of the condition and the strategies utilised by them in this process, there was much less uniformity in their experience. The research reported on here is an important contribution to knowledge of chronic illness experience, particularly in relation to fibromyalgia in SA. By bringing to light these strategies and adaptations, the discrepancies between medical accounts of recommendations for treatment, and lived experience of the condition as told by people with fibromyalgia were displayed through this research. It is a useful insight into the dynamics, complexities, and challenges faced by those with the condition after the point of diagnosis. This is a perspective that is scarcely explored in patient narrative research, especially in the context of SA (Keikelame and Swartz, 2013).

As an illness experience, fibromyalgia deliberately requires flexibility on the part of the patient, practitioner, health care services and support structures involved. This is due to the unpredictable nature of the condition where triggers and manifestations appear randomly and are often unknown or remain unaccounted for through biomedical indicators (Glenton, 2003). Biomedicine, as an institution, is a source of authority on matters relating to the body, illness, health, and disease (Lupton, 2003).

The legitimacy of fibromyalgia as an illness experience rests on the capacity to acknowledge multiplicity as a feature of the condition. Additionally, within a spectrum of severity and manifestation; there can be pockets of explanation and treatment recommendations that are sufficient and effective in addressing the condition (Madden and Sim, 2006). Without these base assumptions however, the organising mechanisms and desires for simplicity inherent in the medical categorisation process, enacted through diagnosis, take over and dismantle the ability of conditions like fibromyalgia to be accommodated within biomedical explanatory frameworks (Jutel, 2010).

Fibromyalgia, as discussed, requires holistic and flexible approaches that respond to the condition as a multiple and complex entity, where the offer of effective treatment supersedes the need to account for the causes and manifestations in a rigid set of narrow categories. Biomedicine is a powerful bureaucratic institution in many societies, and SA is no exception. As the official source of healthcare and knowledge, it maintains its prominent position through its effectiveness in dealing with matters of health and illness. It also achieves this status by ignoring those components of experience and practice that it cannot, or does not; want to account for (Dumit, 2006). There are also disparities within the structure that produce differential outcomes in the experience of interacting with the institution, its facilities, practitioners, and support structures, such as medical aid schemes (Potter and McKinlay, 2005).

The dissemination of knowledge and practice standards within the institution of biomedicine is also uneven and the consequence of this process is that approaches, information, and

treatments are applied in a scattered manner that often do not support the patient (Mik-Meyer and Obling, 2012; Raff et al, 2014). As Claire explains, having knowledge of her symptoms and the effects of her medication are major factors in allowing her to feel empowered while managing her fibromyalgia. She noted in her diary that,

> Although I am glad to have scratched another medication off my list, and I feel happy that I was able to work out that both Wellbeutrin and Lyrica cause severe headaches rather than relieving anything it feels like a vulnerable place to be. I consider myself fortunate to work in the context that I do where I have a reasonable working knowledge of the medications that I use, and have a better understanding of the side effects of the meds that I take. I feel for people who don't have this knowledge because I could easily have ended up in a position where I would be taking more pain killers to treat the effects of meds that are meant to help.
>
> *Wellbeutrin is an antidepressant that works on Noradrenalin and Dopamine pathways. The benefits of it is that it doesn't work on serotonin (hence avoids side effects) and works on the same systems that Ritalin does in terms of being motivating, so the idea of using it in fibro is that it gives and energy boost. I found that it gave me horrific headaches, but only made this connection after talking to a psychiatrist about a patient, and she remarked that Wellbeurtin can cause headaches and because of this she didn't want to prescribe it to a patient who is a known headache sufferer. I quietly absorbed this gem of information and decided to wean off the Wellbeutrin to find a massive improvement in my headaches.

Conditions like fibromyalgia are recent discoveries for biomedicine, and are plagued by continued uncertainty in the face of diagnosis, prognosis, and treatment (Stockl, 2007). Partly because of disparities within biomedicine and the many approaches that circulate within practice, patients with fibromyalgia sometimes encounter the diagnosis and experience the process as being "offered a label without an explanation", as was the case for the participants of this study. The disconcertion extends when their diagnosing practitioner is unable to offer a clear prognosis, and identify the path of their 'sick role' (Koch, 2012; Wolfe et al, 2011).

Most damaging in the process of interacting with biomedical practitioners is often the ineffectiveness of treatments recommended, or where there is no symptom alleviation offered in the medical encounter at all. This was shown in Chloe and Shreela's narratives, where they both were prescribed medication that did not alleviate symptoms and gave them adverse side-

effects, which meant they discontinued treatment. It was also clear from Connie's experience of receiving a diagnosis, but no treatment or prognosis when being told she had fibromyalgia, that the vagueness surrounding this process is disconcerting and disorienting (Stockl, 2007; Glenton, 2003).

This leads to further searching, on the part of the patient, for an explanation for their symptoms. It is an attempt to grasp at the parameters of their illness and medicines that will reduce the severity of their experience, in order to hopefully manage and overcome it. The decentralisation of the responsibility and knowledge around the condition, from the practitioner to the patient, is an important characteristic of conditions with uncertain aetiologies, like fibromyalgia. This is because the patient increasingly becomes the "expert" on their health and their condition. While biomedicine and its practitioners continue to play a supportive role in the process, much of the information, care, and treatment for the patient happen outside of the institution (Wolfe et al, 2011).

As illustrated in Helena's narrative, the ineffectiveness of the treatments and care offered by biomedicine in the course of her illness career with fibromyalgia led her to explore holistic, alternative sources of healthcare. She explained that,

> I nearly died on allopathic medication and I had to make a choice. Well, it didn't leave me much of a choice. I was on a fairly severe cocktail of medication and my body started to crash, my organs started to fail. And the reality is, and it hadn't taken long, because I had only been on meds for about three years. And I realised then that I was either going to die, or I was going to make a different choice, and I have subsequently been on naturopathic. I'm homeopathic, the truth is I practice integrated medicine for myself. I acknowledge the need and the use for the idiopathic [medicine], but I have weaned myself [off].

It is also important to note that some patients experience rejection, or felt the diagnosis offered was not accurate, and in turn disassociate from biomedicine as the primary source of their knowledge and care for their condition. Helena commented that,

> I went through a really horrible period for three years. I was barely living a life. The pain was extremely debilitating. It was often intolerable. You start the cycle of painkillers and non-inflammatory and all those sorts of things. Nobody could help me. They then started to send me to the realms of the specialists. Incredibly expensive on every level. Physically expensive, emotionally expensive, psychologically. It's a battering. You take a battering because everywhere you turn nobody finds anything, and yet you know that you're experiencing this. And sadly they don't, the medical profession is not a particularly empathetic profession. I think, by in large, you find exceptions. I don't want to brush everybody with the same brush. You find exceptions, and I had the opportunity to work with some very caring physicians but they were still unable to give me answers, and by way of process of elimination over three or four years I eventually got to a rheumatologist at the Sandton Clinic who diagnosed me. And as I say, was particularly unhelpful and simply told me I should take an antidepressant because I was depressed.

Despite this discouraging experience, Helena is cautious about distancing herself entirely from the medical profession, and this shows the nuances of the experience of interacting with biomedicine. There are discrediting, disconcerting elements of the encounter and many still look to biomedicine as the authority, and frequently prefer sources of information and treatment that have a biomedical basis, rather than other systems of healing (Cooper, 2002).

This is because of the powerful and dominant position occupied by biomedicine in most Westernised societies, including SA. While the experience of pain, and associated medical conditions, are often poorly understood, there is partial acceptance and support offered within biomedical practice (Råheim and Håland, 2006). The difficulty becomes apparent and impactful in instances of illness where the person and their conditions are rejected in some aspect of their care and treatment, despite initial accommodation. This was evident in the narratives collected through this research process, whereby people with fibromyalgia encountered legitimacy when they were offered a diagnosis.

However, the participants subsequently felt that their experience was allocated diminished credibility, when their practitioners and the biomedical knowledge and practice drawn upon in their interaction did not result in curative treatment, or even reduced symptom severity (Kirmayer et al, 2004). This is indicative of the uneven dissemination of the diagnosis of

fibromyalgia, and the discontinuities experienced in the consequent attempts to offer a concrete explanation and prognosis for the condition. There are also challenges presented to the traditional, expected route followed in medical interaction, as effective treatments that allow the patient to move within and through the 'sick role' with acceptance are frequently unavailable.

The interaction of unpredictable, contested conditions like fibromyalgia with the rigid institution of biomedicine is often full of tension, as the former presents direct challenges to the efficacy and potency of the latter in managing and treating illness. The ability of biomedicine to partially account for fibromyalgia and other contested conditions means that aspects of the condition are incorporated and addressed within biomedicine, while other components of the experience are uniformly excluded on the basis that they cannot be adequately handled by the institution (Mik-Meyer and Obling, 2012). The challenge is further exacerbated when the patient re-enters society following these interactions, and finds that they are unable to draw on care and support from other institutions (Ell, 1996).

These include workplaces, family and peers, and the medical aids that play a critical role in accessing and financially supplementing treatment. The patient struggles to access support, care, and treatment directly as a result of the diminished legitimacy they have for their experience, because of the contested nature of the diagnosis of fibromyalgia. Fibromyalgia requires buy-in for the belief in the credibility for the diagnosis, which is effected through a recognising practitioner and an articulate patient. The interaction, if it is to be productive, has to take place in an environment that accepts the diagnosis for its nuance, complexity and multiplicity. It has to allow the patient to access treatment that can be individually tailored, and often requires an experimental approach to figure out what is effective in addressing the condition (Campbell et al, 2011; Raff et al, 2014; Ong et al, 1995).

When the patient moves beyond their diagnosis and into the process of orientating themselves with their illness and discovering how to manage it as a chronic condition, they are simultaneously interacting with a range of institutions that enable or limit their capacity to cope with their condition (Travers and Lawler, 2008; Åsbring and Närvänen, 2004). The

institutions play a critical role in shaping this process and its outcomes and, as evidence by the narratives analysed in this research study, these additional interactions have a large impact on the experience of fibromyalgia in the SA context. Therefore, it can be seen that beyond the immediate urgency of overwhelming symptoms, the environment, institutions contained within that society, and the interactions between them and the patient have tangible effects on the way that people live with the condition, and are able to move through their illness career (Cooper, 2002; Dumit, 2006; Werner et al, 2003).

In discussing the diagnostic category of fibromyalgia, Crooks et al (2008: 1838) note it is still "a 'controversial' illness in that there remains no consensus regarding causes or treatments. One consequence is that some people living with the syndrome [fibromyalgia] receive little legitimation from certain health care practitioners, government agencies, and private insurance companies". This echoes the experiences of some of my participants, who perceived that their medical aid insurance would not cover treatment for their fibromyalgia on the basis that the condition had limited medical legitimacy. Claire discussed her medical expenses and noted that her son's medication impacted the provision that could be made for her healthcare costs. She explained,

> **Claire:** Ja… his meds… I mean his meds cost about 2 grand a month. My meds probably cost about a grand. So I mean its remarkable that we made it this far… but… I mean the medical aid, I speak to them, they still won't recognise fibromyalgia as a chronic condition. They're not willing to…
>
> **SC:** Which one are you on?
>
> **Claire:** I'm on the Executive Plan of Discovery
>
> **SC:** Ok, so that's the highest level of theirs?
>
> **Claire:** Ja. Ja. And… you know, they advertised it as being the most inclusive benefits for chronic illnesses and that… but they're not willing to acknowledge fibromyalgia as a chronic illness and they certainly will not acknowledge ADHD as a chronic illness

Crooks et al (2008), in discussing the extent to which women with fibromyalgia embrace or reject labels and identities associated with disability following the acknowledgment, both

personal and medical, that they were chronically ill. Crucially they explain that the "interactions that women who have developed FMS have with health service providers, professionals (also termed "legitimizing agents" by Johansson, Hamberg, Westman, & Lindgren, 1999) become particularly important in determining how embodied performances of ill womanhood are read by the self and significant others" (Crooks et al, 2008: 1838). Helena described a meeting she had had with a medical aid company in attempting to financially manage her fibromyalgia with them. She explained that,

> But the medical aids make it very hard. I've been fortunate because I've been financially able to afford it. I had a meeting, in fact it was interesting. I tried to record who put the process, in fact, the lady who helps me with my medical aid she, the agency, she knows of a woman at Discovery whose responsibility is to consider chronic illnesses, and obviously they are faced with the dilemma of the fibromyalgias, the lupuses. Lupus is getting a little more coverage than Fibro. Chronic fatigue syndrome as opposed to M.E, you know all those sorts of things. And she managed to put a meeting together, and I was very grateful for the fact that they took her quite seriously and she came with a team of three of four people that were dealing with different aspects of it. The long and the short of it was they they're not particularly interested, they cannot acknowledge it, they cannot make any accommodations for it. They make no contribution unless of course you are on purely allopathic medication.

Her narrative reflects the difficulties presented with fibromyalgia experience, where the status and recognition of the condition undermines the ability of institutions to address and interact with patients around their treatment needs effectively. In the study detailed in this thesis, there were rare instances of discussion around disability and disabled identity. Having said this, many participants spoke about disabling symptoms, and in realising the chronicity of their condition, the identity alterations, lifestyle changes and accommodations made as a result of their illness all relate to the notion presented by Crooks et al (2008) of "ill womanhood". This is because the participants, in relating their illness experience with fibromyalgia, also spoke about the impact on their gendered identities of being women, daughters and mothers particularly (Mik-Meyer, 2011). For example, Claire spoke frequently of her worry that she was not being a "good enough" mother because she had to put her health before anything else.

Practitioner-patient interactions

As analysed earlier in the "diagnosis" chapter of this thesis, the practitioner plays a vital function in the process of encountering fibromyalgia. The capacity of that practitioner to comprehensively explain what is known about the condition has a foundational impact on the subsequent vision and direction of the experience of the condition. Importantly, in fulfilling another function of being a medical practitioner, the doctor or specialist should also dispense medications and treatments that attempt to manage the symptoms, if not cure them (Morris et al, 2011; Åsbring and Närvänen, 2004). This is a standard expectation of the interaction, and is often the primary reason medical help is sought in times of illness. The process is not straightforward, however, and is complicated when conditions that have uncertain aetiologies, and do not have readily dispensable treatments attached to the diagnosis, are presented (May, 2005). This is the case with many conditions where pain is a core symptom. It is especially seen with fibromyalgia experience, as the expertise of the practitioner is tested by confounding symptoms and treatments that are seemingly ineffective in alleviating the person from their condition.

Lupton (2003: 124) explains that if "the illness is particularly severe, complex, disabling or chronic, patients may be so ill or anxious or both that they are desperate to put their treatment into the hands of someone else deemed competent to deal with the problem". Fibromyalgia is also a curious phenomenon for the practitioner-patient encounter, as the knowledge surrounding the condition is relatively recent and constantly changing, with different and occasionally clashing explanations being offered through medical discourse. There is a reliance on the practitioner for them to be up to date, authoritative, and certain in their prescriptions and predictions of the condition. Regardless of the outcome, the diagnosing encounter appears to be a powerful moment in the experience of fibromyalgia. Chloe explained that the expense of medication and lack of other treatment options strongly impacted her help-seeking behaviour. In our interview, she related that,

> **SC:** When did you start seeing that GP? Or stop seeing him?
>
> **Chloe:** I only saw him once and that was… I guess a year and half ago. I just, I stopped seeing him because… once again, the things he gave me didn't work. They were expensive and… ja. The only thing that has ever worked is Provigil.

SC: Which is what?

Chloe: It's a very expensive thing that they give to… narcoleptics.

Werner and Malterud (2003: 1409) explain that "appropriate assertiveness, surrendering, and appearance" is undertaken by people living with chronic conditions on a continuous basis as they adapt their condition into their life. In this interaction, there is reliance on both the patient to present themselves as needing care in an articulate way, and the practitioner to recognise and address their experience appropriately (Potter and McKinlay, 2005; Åsbring and Närvänen, 2004). Connie, Frances and Teresa demonstrated this in their narratives, where they articulated the clarity they had come to regarding the meaning of their symptoms, and the methods of controlling their exhaustion and pain. Their experiences were also evidence of Skuladottir and Halldorsdottir's (2011) assessment of different interactions that produce the needs that underwrite chronic pain management.

In the case where a practitioner offers explanations that make sense to and support the patient, then a positive relationship can be established between the two. Additionally, the attempt to orientate and treat fibromyalgia as a chronic condition takes place within that continued encounter. However, in the case where the practitioner offers either vague explanations or ineffective treatments, patients leave with the diagnosis and seek assistance elsewhere. In this scenario, there can be negative consequences for the perception of the legitimacy of the diagnosis, suspicion of other practitioners, and feelings of rejection and helplessness on the part of the patient (Mik-Meyer and Obling, 2012). This was demonstrated by Chloe, who had been diagnosed in 2007, and found that her diagnosing practitioner could not offer her treatments that dealt with her fibromyalgia effectively. She explained how another practitioner she had seen explained her condition to her better than her previous practitioner had done. In the description, she also displayed her sense of desperation to find effective treatments, and how this drove her help-seeking behaviour,

> Um… when I catch myself being super happy and healthy, (slight chuckle) I get worried 'cause I know that… an episode's coming, because it's always like best before the crash. One GP that I started seeing… and then I stopped… as is always the case with these things… um, he was a homeopathic GP, so he did both forms… and he explained it in a very simple way,

> that fibromyalgia- and this is just one theory, and it's not a very well supported theory but it makes sense to me… that it affects your cells in a way that you can't flush out toxins… as easily as people without it… and so what happens is your cells will absorb all these toxins… and everything is hunky-dory and then they get too filled with these toxins and then there's a flushing out and that's when you have your episodes. Whether that's true or not… that… it makes sense in terms of the patterns. It's really great, and then it crashes.

Chloe had experienced much frustration with treatments prescribed which had iatrogenic effects, such as extreme and enduring migraines. In accepting fibromyalgia as part of her life, she undertook a voracious interest in the subject. She was sceptical about the role of practitioners in the management of fibromyalgia, especially in light of their inability to offer her treatments that directly alleviated her pain and exhaustion which did not come with additional side-effects (Barker, 2008). In describing her treatment regime and how she was currently coping with her fibromyalgia, Chloe showed the seemingly random collection of advice and treatments she had encountered and tried in the course of her interactions with various practitioners. The treatments included medications for anxiety, depression and pain alleviation, as well dietary changes and exercise recommendations. In her interview, she related that most of the treatments she was prescribed did nothing for her, including those frequently recommended for fibromyalgia, such as Cyprolex and Cymbalta. In an above passage, she mentions how effective Provigil was in reducing her symptoms. However, later in the interview she lamented the expense of the medication and how prohibitive it was, and that, as she did not have medical aid, there was no way she could afford it. This relates to a later theme, which analyses health behaviour and treatment usage in line with medical aid access and coverage.

Finding a practitioner that will recognise your experience as meaningful and legitimate is a critical part of the process of adapting to and accommodating fibromyalgia into one's life (Werner et al, 2003). The security found in practitioner-patient interactions where a patient feels secure in utilising the label of fibromyalgia and is confident that they are being cared for appropriately is another key component that drives the patient towards being able to cope with their fibromyalgia (Skuladottir and Halldorsdottir, 2011). Developing a relationship with a practitioner, where trust and validity are easily exchanged between patient and practitioner,

transforms the consulting process from one of distress (found pre-diagnosis) to one of success. This is not unique to fibromyalgia; rather it is an important part of managing many chronic conditions that a patient perceives they are supported and that they receive appropriate care from their practitioner (Sim and Madden, 2008; Gilson, 2003; Bieber et al, 2006).

Karen described the scepticism she felt having searched for a diagnosis, and the important shift that occurred in her illness experience having encountered a recognising practitioner that a friend of hers had recommended (Barker, 2008; Werner et al, 2003). She commented that,

> **Karen:** I think also just like the experience that I went to… like searching and searching and searching for where… I don't know if it's… inexperience or… if it's not a common thing but I ended up going to three different doctors, taking blood tests…
>
> **SC:** Three different GPS?
>
> **Karen:** Ja. Taking x-rays, doing a scope… things like that. And then when this girl actually told me about it, she was like, "listen, just go to this doctor" and it was like… the symptoms and everything add up… so I think that the experience, also, that I went through actually… makes me feel like people… like I firstly thought I was like… am I actually being crazy about this? Am I imagining it or am I being a hypochondriac? I don't know. All that I know is that when I'm not feeling well, like my body is not well, like I'm not working well… everything, ja, you get exhausted and you get frustrated. So frustrated. And I think actually getting an answer was the biggest hope that I got. Now you know, and you can… just having an answer… and then I can do my own research and finding out what it is and how I can… you know, cope with it. I think that experience actually made it very sceptical for me to… to interact with people about it.

Karen combines peer support, a recognising practitioner, a label and self-management of her condition in coming to terms with having fibromyalgia. This is reflective of the fact that once a diagnosis has been attained and treatment is recommended, the burden of responsibility naturally shifts into a collaborative space of managing the condition, through the use of self-care and selective consultation (Gately et al, 2007). For example, Connie, a mother of two from Johannesburg, who had lived with pain for 20 years, explained the importance of her relationship with her physiotherapist, and the positive impact it had on her treatment and

recovery. Earlier in the interview, she had related how treatment from other physiotherapists had had iatrogenic effects, which underscored for her the difference between them and the practitioner she was currently consulting. She explained that,

> Physio brings relief. But the right physio. Marco is very good with his hands in the sense that he can feel and I can go to him and tell him, "Marco I've got a pain but it feels more like a nerve than a muscle" or "this is more like a muscle than a nerve" or "I don't know, but I think it's torn" and he'll go in and he'll tell me, you know, "yes". Or I'll tell him, "Marco this thing wants to click" and then he'll tell me "it's not supposed to click. If it clicks we've got a problem". He's very, very, very good. So we had a nice relationship like that. But he pulled me through.

Connie was able to articulate not only her needs, but also her sense of what might be the presenting problem (thereby indicating her awareness of herself and her condition) with a practitioner that respected her perspective, and was adaptive to her. This relationship and institutional response allowed Connie to move from a chaotic experience of searching for treatment and practitioners that could work for her, and towards recovery (Skuladottir and Halldorsdottir, 2011; Åsbring and Närvänen, 2004). Having experienced both outright disregard for her pain as a legitimate experience, and the offer of a diagnosis without any explanation, earlier in her illness career, trust and confidence in her practitioners was vital for Connie in the management of her fibromyalgia.

While she still lived with relatively severe symptoms, the responses she and her practitioners had shaped enabled her to live more successfully with fibromyalgia, and cope with it better than she previously had done (Gilson, 2003). She knew the triggers that indicated the first hints of a flare-up, and so in addition to maintaining better health in a holistic sense, she also knew to go to her GP immediately for treatment in that circumstance. These are important findings arising from the research undertaken here, as the processes and factors involved in gaining and retaining the diagnosis are displayed. The experience of the patient in this encounter is an area of research that is often neglected, and this is particularly seen in the context of SA. Therefore, this study and these findings contribute an innovative, unique perspective of living with chronic pain and negotiating diagnosis, prognosis, treatment, social support, and institutional interaction in this environment.

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Prof Meyer, in his interview, described how most of his patients with fibromyalgia see him four times a year, after the initial set of consultations. Once treatment has become routine, and the condition has become more normalised into the person's life, the role of the practitioner transforms into one of an assistant and facilitator to the patient's management of their chronic condition (Åsbring and Närvänen, 2004). With the reduced urgency, and when symptoms have retreated from the chaotic apex of the severest state of the condition, the practitioner falls into the background of the patient's healthcare patterns, and family and peers take a more prominent position. Finding an effective treatment regime is crucial and can only be done with the assistance of various healthcare practitioners. This is not simply for the expertise they offer, but also for the access they provide in prescribing medicines and, importantly in the SA context, in negotiating with medical aids, a theme explored later in this chapter.

Discerning the boundary at which normalised illness required further attention was a delicate balance for the participants of this study. It was essential that the patient was highly aware of the aspects of their condition which were in their control and could be handled through self-care, and which components had to be addressed with the help of practitioners. Furthermore, being knowledgeable about how their medications functioned, and the strategies that were effective in managing fibromyalgia, served people living with the condition well. Arnold et al (2012) and Ablin et al (2012) noted that patient education is critical to successfully coping with fibromyalgia, as well as correct and appropriate medication use. This was reflected in Shreela's case when she related how a proposed trip to the US required the support of her current partner and the difference of the care he offered and approach he took to her illness compared with her other partners. She related that,

> And so… what happened was… um… I was on these meds for about 3 weeks maybe, 4 weeks… and then I went to the US. And the most important thing for me was how supported I felt. Because Michael stayed with me throughout… he just stayed with me… when I was just weeping every single day… and was on the edge of giving up on going to Yale. And he was the one who said to me "I would rather have you fail trying than not go at all. And so I am going to take you to the US. I'm going to come with you and I'm going to stay with you until your meds… until you've stabilised on the meds". And we organised my trip in such a way that I didn't do a 22 hour flight. We actually just flew overnight to… I think… where did we go? We went to Amsterdam. And then we… uh took a train to Belgium and we… I… we

> rested… basically I rested there for a week and then we went to the US. And he stayed with me for 3 weeks. And it was just… I mean none of… neither one of my other two partners would, would have done that. You know… um in fact in both cases… whenever I went on a journey… away from home for my own academic development; the partner broke off the relationship, the marriage. So it was very odd in this time for me, you know… here was a man who was actually prepared to… so that was amazing and I have not looked back since then. And that's partly why I'm still in good health, you know, since, since I've been… when I was on Chinese meds I was… I was… I was OK but I would dip. And it wouldn't kind of hold me on a relative equilibrium… you know I mean, nobody is on… lives on a straight line anyway but for me it would just… do that even on the Chinese meds you know… and on the conventional meds I've just been like a normal human being…

The support he gave enabled her in managing her condition, and allowed her to adapt to and incorporate the knowledge and strategies she had that enhanced her sense of wellbeing (Arnold et al, 2008). The point here is that the combination of support structures provided by her partner and practitioners, and the medications she could use, as well as the body of knowledge she had developed over the course of her illness career, enabled Shreela to cope with her experience more successfully. The passage below also highlights the adaptations she makes to her treatment practices in line with known stressors and triggers, such as an increased workload. In relating her present treatment regime, Shreela explained,

> So I'm on 75 mils of Zoloft. Um I think its 7.5 milligrams of Zopiclone and 25 milligrams of Lyrica. And I continue to take the Derybos, just one scoop every morning. I started off with 3 scoops with one scoop in the morning and one in the afternoon. I have to be careful with how much I exercise. Because I started yoga at the beginning of last year and I was doing it for about 3 months and then I dipped a little bit into slight fatigue and the… the herbalist that I see here, actually I see her more as an acupuncturist… than as a herbalist… she suggested that I cut down a bit on how much exercise. So I um… I still have to kind of figure that out but ja… and I go for acupuncture regularly… uh when I'm teaching, once a week… and when I'm not teaching, once a fortnight, once a month.

Workplace interactions

Having previously experienced severe, debilitating symptoms, and going through a lengthy process of attaining a diagnosis, it was clear that Shreela's quality of life and recovered state of coping with fibromyalgia had much to do with the interactions she had that enhanced her wellbeing. Working in a job that was adaptable, and allowed for manoeuvring around her condition served Shreela well. Her schedule was flexible enough to accommodate her need to rest and consult more frequently with her acupuncturist in times of stress. Her experience is well explained through the use of the "illness flexibility model", as her attendance requirements did not pressurise her enough to have to work while ill. Additionally, the nature of her work meant she could adjust her workload and treatment schedules around her duties when they were more or less stressful (Hansson et al, 2006).

Shreela had not disclosed her condition to her employers, and felt that it should not be a part of her workplace identity. This connected with other participants in the study, who felt insecure about the potential of compromising their identity as a good worker. In spite of not discussing her condition with her employers, the nature of Shreela's work had enough adjustment latitude to allow her to accommodate her symptoms, and fulfil her duties in a manner that supported her management of her condition (Hansson et al, 2006). As discussed earlier, workplaces that could not accommodate employees with conditions that were elusive, unpredictable, and had low medical prestige (such as fibromyalgia) were perceived to be hostile, and were not assistive in the individual's management of their condition (Album and Westin, 2008). Especially in the stage of the condition when symptoms were infrequent and largely under control, people living with fibromyalgia found it unnecessary to tell their employers about their condition.

Karen, a 25-year-old university lecturer living in Pretoria, described her anxiety about the effects of her condition on her ability to perform her work duties, and showed how her inability to discuss condition led to her enacting workplace presenteeism. Karen experienced perceived pressurised attendance requirements, as she felt she could lose her job if she did not show up. The combined burden of "economic loss, accumulated work tasks - [or the potential of] workmates having to replace [her]" as well as her unattended students, were all

considerations in Karen's decision to go to work despite feeling unwell (Hansson et al, 2006: 2184).

The chronicity of her condition, the fact that she often felt sick, tired, and sore, as well as the awareness that her will was a large factor in her overcoming her symptoms and coping with her condition, all led Karen to push herself to go to work, rather than being frequently absent. She explained that,

> **Karen:** I end up pushing the snooze button like 10 times, and then last minute I jump in the shower and then I'd go… but then you're like still half asleep and you're grumpy and… sometimes you get to work and you have your five minutes of getting your things together, it's just such a rush the whole time. And you're like, listen, suck it up and deal with it.
>
> **SC:** Ok so you do a lot of that with yourself?
>
> **Karen:** Ja.
>
> **SC:** And is it because… just as an alt scenario. If you told work that this was a prob and it was exacerbated by stress…
>
> **Karen:** I'm worried that they'll… they don't want me to work there then. Because you…
>
> **SC:** Really?
>
> **Karen:** Ja, I don't know why… but you want your employees to be punctual and be chirpy… because I work with students you know, they can't let me be in a bad mood… like half of the week. So I'm worried that it'll actually affect my work. But ja, I've never had the courage to actually tell them about it. Maybe that would be a good step, actually.

There were elements of both felt and enacted stigma related in many of the narratives offered through the interviews. Stigma is often attached in implicit and explicit ways to people, and the chronic conditions they live with (Scrambler, 2009). Particularly in relation to workplace interactions, there were many complexities that contributed to the silence around fibromyalgia in these environments.

The extent of symptom manifestation played a critical role in the disclosure of diagnosis, and where the condition could be concealed, it was. This is often the case with chronic illnesses, whereby the individual fears or anticipates that the condition they live with will become all that is known about them, and it will drown out other aspects of their identity (Werner et al, 2004; Jackson, 2005; Åsbring and Närvänen, 2002). For many of the participants in this study, maintaining a work identity where the character traits of being a capable, reliable person was important, and much was done in order to keep that image untarnished (van Hal et al, 2013).

For example, Chloe, having moved into freelance work as the result of her fibromyalgia, felt a lot of anxiety about being perceived as "flaky" or letting people down. She spoke about the fact that having to explain fibromyalgia, as opposed to other illnesses like the flu, led to her worrying that she would be misunderstood or perceived negatively. She commented that,

> Ja. And it's so funny, I mean if I have flu, I tell people I have flu, "they're like ah, shame ja I get it, it's cool, we understand". And I don't get panicky about it; I don't feel like I have to over explain anything. But when its fibromyalgia, I get this sense of panic like… who am I accountable to in this time? Who do I need to apologise to? Who do I need to explain this to? And there's this big sense of panic. And… like, no-one is going to understand… in their minds they probably do understand or it's not that big a deal to them. It's not something that I really have to worry about. But in that moment its… like… this thing that I just can't make it other people's problems but I probably end up doing the opposite in some cases.

Working in a freelance position meant that Chloe had the flexibility to accommodate her fibromyalgia, by resting when necessary, and in continuing to work for the same company, they were aware of her condition. The additional layer of pressure, added by her self-perception and concern over her identity and ability to work to a standard she was comfortable with, was a challenge Chloe and other fibromyalgia patients continually faced. Similarly, Claire had also encountered queries over her capacity as a reliable worker, and she speculated that her illness was being used to undermine her in the workplace. She articulated, the most clearly, the sense of both felt and enacted stigma that followed the disclosure of her diagnosis. Interestingly, the institutional response offered by her workplace, and the

management there, was one of support and accommodation. However, in the direct interactions she had with her immediate boss, she felt targeted and invalidated.

Claire had also noticed that the care and support given by the management was partial and appeared as a one-off, rather than being comprehensive and continual, which would have been preferable given the nature of her condition. Her symptoms were still relatively overwhelming and, when necessary she had to miss work to recover from them. She explained that,

> I don't personally think the doctors have a clue what it's like. I mean I just don't think they do. Ja, I mean I haven't actually thought of that but I mean basically I would be unable to hold down an 8-5 job. It's not within what I'm capable of. I can work 7 days a week but it… it's blocked [periods of time].

This incapacity was discontinuous for her in her self image as an effective worker, who managed her condition in a way so that it did not affect others. Ultimately, Claire moved out of the hospital work setting she was practicing in and started a private practice, which gave her the flexibility and leeway she needed to accommodate her condition. She described some of the comments made to her in relation to her condition, and stated that,

> **Claire:** And also… I mean ja… I think… just how… people kind of see a chronic illness as almost like… impending incompetence… and not something that if you accommodate you can keep this person as a resource. Um… but you know… it doesn't make them incompetent.
>
> **SC:** Ja. I mean is that how you've experienced it? In the way yours has been treated?
>
> **Claire:** Ja, I've kind of experienced very much as, "we know that you're a good therapist but…"
>
> **SC:** And the "but" is?
>
> **Claire:** The "but" is "but you know, like with your health… your this and with that… you know, it's just hard for you". And when I speak to my boyfriend about it he says, "but if they're acknowledging that you're a good therapist, why are they not doing whatever they can to keep you?"

For Claire, the perception that her position and quality of work as a therapist could be compromised by a chronic illness was something she experienced as acutely delegitimizing. Despite having the support from senior management, and feeling valued when she was asked to consult specifically because she was known to have fibromyalgia, she also experienced stigmatisation for her condition from other colleagues at different levels of the organisation. Most of the participants in this study were working in jobs that allowed them to complete work at their own rate, and within flexible hours. The match of an accommodating workplace or a job that gave freedom in terms of work duties and completion times, allowed many of the participants in the study the opportunity to conceal their diagnosis from their employers, and manage their condition outside of the workplace environment (Higgins et al, 2012). Those who had lived with the condition for a number of years felt it was unnecessary to tell their employers, when the individual had normalised their symptoms, and had developed strategies which meant they were rarely absent (Richardson et al, 2006a).

When they had developed an articulate and palatable version of their diagnosis and its meaning, then it was more readily shared. Where sympathy and empathy were easily offered, there was also encouragement felt to disclose their condition. It was a delicate balance of needing to inform, but also showing themselves to be still capable. This relates to a bigger theme of who is told generally about chronic illness, and especially in cases where the condition is contested (such as with fibromyalgia), who can be trusted to receive the information as it is intended (Giordano and Lindstrom, 2010). Some participants were protective of their diagnosis, not wanting it to impinge on their identity, despite its constant presence. Many spoke about the fact that their illness did not come up often, unless the opportunity was presented by the onset of overwhelming symptoms, and that telling people about it was a process not easily undertaken. The workplace was a tangible site of tension and decision for the people spoken to in this study. However, where work could be done without being impacted by fibromyalgia or in affecting the condition's manifestations, then disclosure of diagnosis was also not necessarily an issue.

Medical aid and bureaucracy

One of the most significant and original findings to emerge from this research study has been the impact of medical aid schemes on healthcare access, and consequent strategies utilised by people living with fibromyalgia in enacting healthcare behaviour. There is consensus that the level of flexibility and reflexivity required to effectively address fibromyalgia, on the individual and societal level, is high. It also stands in contention with the immovable and organisational structure of medical aid schemes, that use narrowly defined categories and recommendations as guiding principles of the economic modelling linked to healthcare access (Namane, 2013; Wadee et al, 2003). Barker (2008: 33) notes the crucial role of "practitioner compliance" in this process, as "patients recognize their potential conflict of interest with economizing health care providers and organizations, the managed care environment will increase the likelihood that patient-consumers will persist in realising their demands".

In the SA context, the inequity found between the private and public healthcare sectors has a tangible effect on healthcare access (McIntyre et al, 2007; Stuckler et al, 2012). Particularly in relation to pain management regimes (which incorporates the treatment of fibromyalgia), there is a need for holistic approaches that utilise a range of services, practitioners, and treatments in the course of addressing a patient's pain, exhaustion and other symptoms (Derman et al, 2011). Pither (2005: 50) comments on the fact that pain management services "have suffered from a historical failure of full integration within hospital management systems, leaving them with a heritage of poor resources". The deficits in these services are more impactful when combined with the inequities that characterise the SA healthcare system, and the general lack of recognition for contested, complex conditions like fibromyalgia in this environment. The participants of this study exclusively used private healthcare, and only a couple of them had encountered dedicated pain clinics. This shows the decentralisation of pain management from hospitals and into primary healthcare settings, where individualised treatment regimes were utilised more frequently than standardised, and hospital-located treatment plans (Rauf et al, 2013).

Furthermore, Mody and Brooks (2012: 237) speak about the fact that the spectrum of musculo-skeletal "disorders in developing countries is similar to that seen in industrialised countries, but the burden of disease tends to be higher due to a delay in diagnosis or lack of access to adequate health-care facilities for effective treatment". This speaks to the contextual factors that affect health outcomes, when viewing particular conditions in specific societies. In SA, the effect of an unequal healthcare system and a disproportionate number of healthcare practitioners working in the private sector leads to a specific characterisation of people who attain the diagnosis of fibromyalgia. In this context, people who are diagnosed with fibromyalgia tend to be from middle-class backgrounds, with access granted to healthcare services through the utilisation of private medical insurance (also called medical id). As explained earlier, because seeking the diagnosis requires so much, in terms of articulating the experience, and in finding a recognising practitioner, people who are able to achieve this task are also seen to have access to fiscal resources that assist this process.

Fibromyalgia as a diagnosis is not a first port of call when identifying pain and exhaustion and, as evidenced by the narratives collected in this study, labelling an individual's symptoms as fibromyalgia often follows lengthy interactions with many practitioners (Ablin et al, 2012). Additionally the level of specialisation required to diagnose fibromyalgia means that the condition will not generally be offered in the first instance of seeking help from a primary healthcare provider, particularly in the public sector (Namane, 2013; Benatar and Fleischer 2008). The repeated consultations, and range of specialists usually drawn upon to clarify the symptoms and label them as fibromyalgia, create a specific image of who is typically diagnosed with the condition in the SA context. In other contexts where a nationalised healthcare service is available to all citizens (such as the UK), there is a less visible class distinction given to fibromyalgia diagnosis (Travers and Lawler, 2008). In SA, however, because of the fact that the majority of practitioners operate in the private sector. Access to this sector, and associated facilities, is limited to less than 15 percent of the population who have medical aid (Mooney and McIntyre, 2008). These factors shape the demographics of who is able to attain particular diagnoses.

The distinguishing feature between those who have medical aid and those who do not, is that they are steadily employed and are generally wealthier than the rest of the population.

Therefore, their fiscal and personal resources allow them to pursue healthcare in a different way from those who rely on government provided public healthcare (Sekhri and Savedoff, 2005; van den Berg et al, 2008). In the public sector, there are shortages in the provision of healthcare services, facilities and practitioners who are serving the majority of the SA population, and the sector is incredibly overburdened and under-resourced (McIntyre et al, 2003). All the people interviewed for this study had received their diagnosis of fibromyalgia in private healthcare settings. In their personal characteristics, they were articulate and persistent, and had received a minimum of high-school educational qualifications.

In the context of SA, this automatically placed them in a higher socio-economic group than the majority of the population. Medical aid access and coverage played a critical role in shaping their illness experience, both at the point of diagnosis, and then later in the treatment and management of their fibromyalgia. The tangible effect of medical aids, in allowing access to practitioners and treatments in the private healthcare sector of SA, distinguishes the experience of fibromyalgia from global understandings of the condition (Namane, 2013; Rosen and Simon, 2003; Thomas and Gilson, 2004). Within the narratives collected through this study, there was a set of experiences that detailed the changes seen when access to medical aid was lost, or coverage for treatments and healthcare practitioner consultations were restricted. This is discussed further below.

This mostly related to the adaptations that the participants had to make to accommodate their condition, and the healthcare context they were interacting with (Timmermans and Almeling, 2009). Furthermore, fibromyalgia was not particularly recognised by SA medical aids, and this meant that people with the condition had to manoeuvre around the limitations what they could afford to do in terms of their healthcare. What this led to, in most cases, was a discontinuation of consultations with their practitioners around their fibromyalgia, and a move towards self-care once the diagnosis had been attained. There was also a culture of consumerism encouraged directly in relation to the presence of medical aids for healthcare supplementation, where decisions of practitioner and treatment utilisation were affected by medical aid availability (van den Berg et al, 2009; Lupton, 1997; Bell and Figert, 2012; Barker, 2008).

Rebecca, a 32-year-old swimming instructor from Johannesburg, also commented on the difficulty she faced with seeking treatment, once her medical aid allowance had run out. She was heavily in debt, and could not yet see a pattern that would enable her to use her allowance more strategically, as the range of conditions and practitioner consultations she had all felt essential. She had issues with her thyroid as well as her fibromyalgia. She explained that,

> I have… other things, have taken… like I mean, I've gone to physio and stuff like that. The thing is that when you apply on medical aid for you know… additional… because your funding [has] run out, they say, no because it's not on their list.

This interaction shows that the medical aid is unaccommodating of the range of Rebecca's conditions, and once the provision provided by the scheme has run out, applying for additional support is met with inflexible denial. She needed to see physiotherapists, a biokineticist and a chiropractor to help with managing her pain and stiffness. She also consulted with an endocrinologist and her GP, all of which led to her financial support from the medical aid to be depleted. This demonstrates a lack of understanding on the part of the medical aid of the multiplicity of Rebecca's condition and the attached consultations. As Thompson et al (2011) noted, comorbidity and severity both play a critical role in shaping healthcare service usage by people with fibromyalgia. This lends support to the understanding that approaching fibromyalgia in a holistic manner with an all-encompassing view that many factors could be producing many aspects of the illness experience and all need addressing in tandem. The flexibility required in addressing the range of conditions she lives with, and the many routes of response that are taken in managing Rebecca's symptoms is simply not found in the structure and functioning of rigid medical aid schemes in South Africa.

Thompson et al (2011: 44) discuss a 2003 study which found that in the United States, the "total annual costs (both direct and indirect) for FM claimants [were] $5945 *vs.* $2486 for the typical beneficiary". They explain that "United States patients with clinically diagnosed FM incur direct medical costs about twice that of their matched controls. This increased cost is

related to the severity of their symptoms… and may be related to the increased comorbidity found in patients with FM" (Thompson et al, 2011: 45). Thompson et al (2011) further assert that any programme designed for the treatment of fibromyalgia should incorporate strategies focussed on decreasing the overutilization of health resources by patients. People with fibromyalgia are dealing with multiple conditions at once, and this means that reducing the experience to a singular entity or cause will entail that much will be lost, in terms of explaining the nature and manifestation of fibromyalgia particularly, but 'central sensitivity' conditions in general (Meyer, 2012; Finan and Zautra, 2010).

Medical aids in SA offer partial or full coverage of medical expenses and, crucially, access to facilities, practitioners, procedures, medications, and treatments that are exclusively available in private healthcare settings. The restricted access to this environment and its resources is a key indicator of the sample demographics found in this study, as only 15 percent of the population has access to medical aid and out-of-pocket payments for these services can be prohibitively high (Govender et al, 2012; Basu et al, 2012). By virtue of their possession of medical aid coverage, the people interviewed in the course of this study automatically had a higher socio-economic status than the majority of the population.

While medical aids give necessary access to health services, they also play a role in limiting access, and this is most importantly seen in the case of a chronic condition like fibromyalgia (Timmermans and Almeling, 2009). As Frances explained, the medical aid she could access through her husband's workplace was unique in the coverage it afforded her. Additionally, the timing of her treatment in line with SA health policy meant that she did not encounter out-of-pocket payments in managing her fibromyalgia. In our interview she noted that,

> **SC**: Which one are you on?
>
> **Frances:** De Beers. It's a pretty small in-house… job. But they've always been very, very good. Never had any problems at all. But I mean those were the days that if the doctor thought you needed to go into hospital you walked into hospital and climbed into a bed. You didn't have to justify… the fact that you were breathing 6 times every minute or whatever… before you went in. Life is very much more complex now… dealing with things. I mean I would be taken into hospital for pain control. For… a week or whatever.

SC: Back then?

Frances: Back then… in the mid 90s. they would happily admit me for pain control time after time, to get things back under… because again… I was my own worst enemy for a long time. I would ignore it and ignore it and ignore it until such time that my body said that is enough, and you are going to collapse in a heap. At which point I would be, admitted. Hospitalised. Where as if… eventually got to the point where… because I couldn't bear the thought of taking pain killers in case that day was going to be painful… I would… then wait until there was pain there and then I would happily say I can deal with this. I'll only do something if it gets a bit worse. And when it got a bit worse I would say, no I'm managing to cope with that… I'll wait 'til it gets worse. Whereas once I had actually got my mind around the fact that if I took something on a regular basis… and didn't let it build up, I mean I could keep myself out of hospital for a couple of months. Whereas I was ending up in hospital every couple of weeks. It was… it was pretty awful for a while… but it was a matter of… and I think that's where the pain clinic at Groote Schuur helped me so much... Was getting my mind round the fact that I actually had to deal with pain as I would deal with a broken foot or whatever.

Fibromyalgia, as a chronic condition, is tricky for immovable structures like medical aids, as the predictability of the condition is low. Multiple factors, creating numerous manifestations and fluctuations in health and illness, make pinning down the parameters of the condition a challenging task (Lupton, 2003; Stockl, 2007). In an institution that desires categorisation, and sees healthcare as a unitary structure that offers a specific form of care, medical aids are particularly challenged by the holistic approaches needed to address fibromyalgia and dynamic nature of the condition (Dumit, 2006). Fortunately for those living with fibromyalgia, it seems that the authority of biomedical practitioners and their status in healthcare provision, means that, when necessary, the intervention of these practitioners in patients' interactions with medical aids seems to positively impact the situation (Cooper, 2002).

It was apparent that there were limitations placed on access to practitioners, treatments, and medications directly as a result of the status of fibromyalgia as a chronic condition, and the lack of recognition offered through medical aids. Strategies developed and changes related to health-seeking behaviour in light of medical aid availability, and the access afforded through

the schemes, was another strand of the findings. From this, it was evident that many of the participants were only able to manage their fibromyalgia through treatments that were available on a pro-bono basis from willing practitioners. This also encouraged a level of self-care, and experimentation to find strategic opportunities of management for consultations with practitioners and treatments (Åsbring and Närvänen, 2004). As a consequence of the interaction with medical aids in order to access healthcare, the people involved in this study were also seen to have consumerist attitudes to their health, where choices, decisions and actions were influenced by economic factors (Percheski and Bzostek, 2013). Social capital and practitioner cooperation additionally played an enormous role in the patient's ability to negotiate around the medical aids, and receive chronic cover for their condition. This is all discussed in the sections below.

However, unfortunately, the overwhelming trend of experience related in the narratives of this research shows that medical aids are actively obstructive in the attempts to manage fibromyalgia as a chronic condition. This is worsened when healthcare is unavailable, because the individual does not have medical aid and cannot afford to pay for healthcare without this supplementation (Percheski and Bzostek, 2013). As Chloe relates below, she was restricted in getting a medication that vastly improved her symptoms on a frequent basis, due to the cost being prohibitively high. As a freelance worker, she was currently without medical aid, and therefore had to alter her health-seeking behaviour and medication use as a result.

This particular medication was not available with medical aid discounts in any case, which is another aspect of the picture that complicates matters further. This also meant that she was being overwhelmed by her symptoms, and was unable to access treatment that would effectively alleviate them. She explained the effects of this medication, called Provigil,

> **Chloe:** OK. It keeps you super alert and basically gives you hectic mental clarity and lots of physical energy. Um… I took it for a month which is all that I could afford, to see if it would work and … man, I've never slept so well, I've never been so personable. I… like my work was fantastic, my work ethic was fantastic… like I could work anytime… um I was just clear and bubbly and I felt like I could rule the world. Um. But it's very expensive and I can't afford it.

SC: How much is it on average?

Chloe: Back then it would have cost about a grand a month. Ja… and no medical aid cover whatsoever. I mean you can ask Ben [her partner], every time we talk about like, oh if I was a millionaire, I'd do this that and the other but the first thing I always say is, I'd put myself back on Provigil (laughter)

SC: Ja. Because it's just too expensive… of medical aid rates.

Chloe: Ja. It's really worth it. If I had the money, I would totally do it. But I just don't… have the money. But that is interesting because… my medical aid… I'm not on medical aid anymore.

SC: OK? Because you don't have full time employment or… what is the case?

Chloe: 'Cause I can't afford it myself and my parents can't afford to pay for it for me. But I mean… it's being worked on. Um… but the only thing that they would ever pay for was… my antidepressants or anti-anxieties that I was… that I was prescribed. That one. And fibromyalgia itself is not recognised, was not recognised at the time by medical aids, and so they recognised that as a depression problem or an anxiety problem and not as a treatment for fibromyalgia.

SC: So it would have to come as a sub-category of depression or anxiety as opposed to a stand-alone condition which would have the knock-on effect of anxiety or depression.

Chloe: Ja. And in fact Cyprolex and Cymbalta which was the other one, are actually prescribed for pain as well. Um, it did nothing for me.

In the passage above Chloe highlights the alignment that is needed between the status of a condition, and the recognition from medical aids, in order for it to be covered. She also notes the additional issue of particular medications that are not included in those covered by medical aids. As she states, Chloe could only get financial support for her anti-depressant and anti-anxiety medication. The treatment she could access as a result was for her depression and anxiety, rather than her fibromyalgia, the latter of which was her reason for seeking help (Skuladottir and Halldorsdottir, 2011).

In contrast, Frances, who had had a series of operations, and whose fibromyalgia had largely cleared up as a result, had never experienced any difficulties with her medical aid coverage.

This fact, she acknowledged, was due to the robustness of the scheme she was covered by, as well as the fact that all her treatments were categorised under medical issues related to her back, and never as directly fibromyalgia treatment. She also noted that the majority of the treatments took place before the codifying of medical consultation and treatment (Timmermans and Almeling, 2009). She used a medical aid scheme accessed through her husband's workplace. She related that,

> **Frances**: I've always had hundred percent cover. It's never been a problem. Look, I suppose when it was first diagnosed… it was really before the doctors always had to put a code down… and absolute… I mean obviously it's not… I don't know the… whether there is a code for fibromyalgia, I've never come across one. I think… most of the treatment I've had would've been covered for under probably arthritic pain or one of those sorts of more conventional type things. Ja, I mean I've never had a problem with any of the drugs that have been… been… prescribed. Um… that's 'cause…
>
> **SC**: And medical aid just pays for all of them fully?
>
> **Frances**: Ja. ja.

The excellence of the care she was able to access at such an early stage of fibromyalgia's presence in the medical discourse was directly impacted by the medical aid she was using, and the fiscal support it offered. The complications seen with the increased privatisation of healthcare, and challenges faced for people with conditions that have uncertain aetiologies and unpredictable prognoses, were more apparent in the people's narratives who had encountered their diagnosis more recently. Liminality characterises fibromyalgia, as wellness and illness coexist on a spectrum. This means that identifying sickness and assigning appropriate responses, in terms of medical treatment recommendations and standardised fiscal support, is a challenge for institutions like medial aid schemes (Glenton, 2003; Mendelson, 2009). Most medical aids have caps on the number of practitioner consultations and medications that a patient may claim for, after which time the cost of treatment must be incurred by the patient without fiscal support. This practice led many of the participants in this study to alter their help-seeking behaviour and turn towards self-care and manage their condition without the intervention of practitioners where possible (Gately et al, 2007).

Prof Meyer only saw patients by referral, and his practice had established a routine set of consultations for fibromyalgia patients. For him, the issue of medical aid coverage was irrelevant, as he had not encountered any difficulties with his patients claiming back from medical aid for their consultations with him. In the case of his practice, the standardised number of consultations (four a year normally) meant that his patients could adapt their health-care utilisation to accommodate this, and use their medical aid claims strategically. Having said this, Claire, a patient of Prof Meyer's, still faced difficulties in getting full coverage for her condition, a factor that was complicated by her child's chronic medication costs, which also had to be accounted for in her family's medical expenditure.

Claire's son had AD/HD, and her medical expenses were incredibly high, between her and her son. She also highlighted the difficulty of the category of chronic illnesses and medical aids, whereby her son's AD/HD was also not recognised as a chronic condition, which then limited her coverage. She related in the interview that,

> **Claire:** Ja, I mean the medical aid… really, what they do to you is that they… they pay for the doctor's visits… I mean we recently…
>
> **SC:** To Prof [Meyer] and to your GP
>
> **Claire:** Ja. We recently ran out of our kind of… our prescription meds benefit. But I mean for me the big thing there is actually not my medication, it's actually my son's medication.
>
> **SC:** That's their threshold really… and so do you just pay for it out of pocket and have a budget for it?
>
> **Claire:** Mmm… it's what it is. And I mean the way that I look at it is… you know, say the medication I need to take on an everyday basis costs like, 50 Rand or 100 Rand… like… if I don't spend that 100 Rand on the medication I'm not going to make the rest of the money I could make in that day so it's almost just like an investment. I have to pay that money, um, to be able to make more money. But that's always the… that's the way it goes in my head, is it's actually not a negotiable expense. I can't function… I can't function without it.

For Claire, hers and her son's medication was an essential budget item and, crucially, allowed her to work which meant that, as a single mother, she could continue supporting herself and

her family. The impact of her condition and the experience of her "ill womanhood" created additional pressure for Claire as person, and she was frantically aware of the limitations imposed by her fibromyalgia and the consequences for her capacity to provide and mother her children (Crooks et al, 2008). This highlights the gendered nature of fibromyalgia, as discussed by Barker (2005) and others, as Claire was attempting to care not only for herself but also her children, and her illness identity as someone with fibromyalgia fundamentally shaped her ability to be a mother in the manner she would have liked.

Claire's position as a single mother meant that duties related to the household and parenting could not be put aside in favour of her own health, and the internalised cost that she carried when her medical aid benefit and allowance had run out was a common thread through many of the narratives of the participants of this study. This was similar to the trend identified by Becker et al (2004) where they showed that medical insurance access influenced both the utilisation of medical practice, as well as self-care strategies. The findings that emerged in the course of this study are an important contribution, as there is little knowledge of the impacts of healthcare utilisation and medical aid interactions, around chronic conditions like fibromyalgia, in the context of South Africa.

Rebecca also spoke about the differential coverage offered by her medical aid for her particular conditions, and the complexity of managing all of them in their multiplicity. She spoke about her strategising, her adaptations when provision ran out, and the role of pro-bono care that was offered by her practitioners, and said that,

> **SC:** And does that cover… the… thyroid and insulin stuff?
>
> **Rebecca:** At the moment, not the insulin and blood tests. They don't cover that.
>
> **SC:** Ok, so would the fact that the…
>
> **Rebecca:** Not on chronic though. If I was diabetic they would put the glucofrodge on chronic, but because I'm not diabetic they won't. No
>
> **SC:** Ok, so is it something you consider… in… choosing who you see and what treatments to accept, the fact that you've got limitations on the medical aid?

Rebecca: Um…. I think so yes, because like I had to stop the physio and I had to… I was lucky enough, although my chiro said I mustn't say anything, my chiro is saying to me, he's not going to charge me like until, you know, medical aid and whatever kicks back in… because I have to go to the bio and I must pay for the bio

SC: The biokineticist?

Rebecca: Yes.

SC: Ok and how often do you see the biokineticist?

Rebecca: Well I cancelled the bio… I mean I was meant to go now, but I cancelled because I just don't have the money. Like so… if my funds are out, then I've got no funds 'til the next year. So I've seen the bio twice and done the exercises and then, thank God, with Boot Camp [an exercise group], which is also not covered by medical aid, 'cause she works on core, its helped a bit, but I mean I've got exercises to do and I need the bio to help me with them because you don't remember what they all are. And … I have to go buy a ball and I have to go, you know, and there's exercises that I need to do… at gym but I don't… you know there's certain things I'm embarrassed to do because I don't know how to do it properly. You know, so… it does put your limitations…

Rebecca's narrative shows the difficulties faced in assimilating the range of advice and treatments she needs to manage all her conditions, and the way that medical aid access undermines her ability to consult with the practitioners she needs to see. Becker et al (2004) assert that there is consensus about the important role self-care plays in the management of chronic illness, but there is relatively little known about how individuals enact these strategies as every day practices. In presenting narratives and experiences of chronically ill individuals living with fibromyalgia, this study aimed to contribute knowledge about the meanings, behaviours, strategies and outcomes of addressing this illness experience in the SA context.

Rebecca was trained in sports massage and so often alleviated the stiffness in her muscles herself when she was experiencing symptoms (Lewis and Johnson, 2006). Her chiropractor had offered to not charge her until her medical aid provision had renewed, in order for her to keep consulting with the biokineticist. The range of practitioners she needed to see was characteristic of the multi-modal approach required in addressing fibromyalgia effectively. Zainab was also receiving pro-bono treatment from her daughter who had recently qualified

as a biokineticist. Along with pain management and a strict exercise, rest, and diet regime, despite constantly being in pain, Zainab had her symptoms under control, and so consultations with her GP were infrequent. Thus, she was largely using self-care to manage her fibromyalgia. She explained that,

> In fact the once he actually hospitalised me where he then put me in hospital, just for… when he stuck sort of weights all over me… I think he felt more I… it was just [chuckles] and you know… I think he treated me more in terms of stress and then also, ja; all that… maybe thought it would do something. And yes, I used to go a lot to physiotherapy but I couldn't handle the physiotherapy because all that… vibration, the once I went for the… dry needling and that sort of basically felt like it bruised the muscle and it was… ja and otherwise I used to get my kids, you know when they were nice and light, then I used to get them to sit on my back [chuckling]… and whatever. And ja, then about three years ago my daughter started doing biokinetics and then she started well, you know, doing the treatment of… massage and exercise, plus massage plus pressure points and kind of … first she wasn't too good at it obviously… that good at it [chuckling]. And so basically in the mornings when I… you know… in fact… before I even wake up I think, it's almost… dream it in my sleep, where I actually move around a lot before I even wake up, roll around, move around you know, stretch around… and that's while I'm still… waking up and when I wake up, also, I try, you know… do a bit of stretching, exercises as well. And… ja if… I have to get to work so sometimes, the pain is… you know… I cannot lift my head or dizzy spells … sometimes I actually vomit and after I vomit I feel a bit better. And otherwise I will… I try not to take pain killers but sometimes, like this morning I took a dispirin. So you know, I might take maybe 2 painkillers a week but I try to keep it to either dispirin or panado, something like that. And… because I've read that even painkillers can… cause the thing… so… and then my diet is very different.

The understanding she has of her condition, and what will bring her relief, is as a result of Zainab's knowledge of the chronicity of her illness (Jackson, 2005). She has normalised the experience of pain and exhaustion to such an extent that responding to it in the manner she does is part of her everyday life. Her daughter's ability to intervene and provide care through her profession as a biokineticist also contributes to Zainab's improved state of well-being, and is an asset she would struggle to afford if Zainab had to pay for it out of pocket, or through medical aid. Claire also received physiotherapy treatments from a practitioner at the hospital where she worked, and she explained that,

> He refuses payment. He's knows that anybody… I mean with my patients who have depression, I always ask them about physical pain because to me you've got depression for from physical pain… I think he knows that I… I just get massive benefit…and I just refer everyone to him but ja, he's great. He was like; staff in the hospital don't pay. So… he can actually… he can… sort my neck out. And then overall improve the quality of life…

This chapter has discussed the impact of institutional interactions on the experience of fibromyalgia by focussing specifically on practitioner-patient interactions, workplace accommodation, and the effect of medical aid in SA on the help-seeking behaviours of those living with fibromyalgia in the country. Additionally, the operational mechanisms of medical aid schemes in SA, and the consequences for people living with fibromyalgia where access to healthcare is limited by the low status of the condition on the medical hierarchy of diagnosis was analysed in this chapter. Critically, the amount of flexibility required to tackle and absorb fibromyalgia as a chronic condition presents challenges to the rigid structure of medical categorisation, which reduces the ability of practitioners, management structures in workplaces, and medical aids to effectively address the illness, was discussed. The next chapter discusses the role of social support in coping with fibromyalgia as an illness experience. This is detailed through explanations of the impact of family, peers and partners, social capital, and the practical care and fiscal support needed in order to manage a chronic, unpredictable condition like fibromyalgia.

Social Support and Knowledge

As discussed in the Diagnosis section of the findings, sources of social support are important mechanisms for coping with the illness experience of fibromyalgia. In providing a space for consultation and validation of the diagnosis of fibromyalgia, and the person living with the condition, people giving support fulfil a critical role in shaping the experience (Bury, 2000). The people who support the individual with fibromyalgia are often instrumental in the ways that complex, inexplicable symptoms and contested, elusive, and confusing illness experiences are understood and managed. As explored in an earlier chapter, practitioners that the person with the condition interacts with are an important pillar of support, in giving their experiences medical legitimacy and meaning. Practitioners also provide treatments that could alleviate their symptoms.

An additional layer of support that underpins this interaction is that which comes from family and peers. People often speak to family and peers about matters relating to their health (Ell, 1996). Lay sources of health knowledge are influential at the junctions of interpreting symptoms, seeking diagnosis, and making sense of the experience. This is particularly seen in the case of contested, elusive, and confusing conditions like fibromyalgia. This chapter will first discuss lay beliefs and definitions of health. Thereafter the important role played by family in the illness experience of fibromyalgia will be explained. The manner in which peers provide support, comfort, and knowledge is then explored. Finally, the body of information accessed through the internet and other media sources by people living with fibromyalgia is briefly discussed, for the important impact it has on public perceptions of the condition.

As discussed in the literature review, social support appears in many forms in the illness experience of fibromyalgia. The family as a prominent source of social support fulfils the functions of providing practical and emotional care for the person with the chronic condition. As argued in the literature review, the family is also the site in which fibromyalgia as an illness experience primarily unfolds. Furthermore as explained earlier, practitioners and peers play vital roles in shaping the experience of fibromyalgia, by extending legitimacy and belief for the person with the condition (Dumit, 2006; Glenton, 2003). The stigmatisation of the

condition by people close to the person with the illness has profound effects on the perceptions and experience, and this is explained in the findings detailed below. Finally, the role of the internet as a source of knowledge for people with the condition and those that surround them in making sense of the experience is explored.

Impact of family support in shaping fibromyalgia experience

The family plays an indispensable role in forming perceptions and health behaviours around approaching and coping with fibromyalgia. The social capital granted through familial systems, in providing access to knowledge and resources that enhance health, further contributes to the capacity of the individual with fibromyalgia to make sense of their experience, and respond to it appropriately. This occurs in a variety of ways; by offering information and advice, recognising symptoms as problematic, ensuring medication is taken appropriately, and alleviating the sick individual from domestic and other obligations (Werner et al, 2003; Åsbring and Närvänen, 2002). For Kate, having her parents support throughout her encounter with fibromyalgia had an enormous impact on her experience of the condition. They were assistive both at the point of seeking diagnosis, and when responding to the meanings and demands involved in absorbing the condition as legitimate and real in her life.

Kate had experienced severe, disabling symptoms and this led to the intervention of her parents taking her to a healthcare practitioner, who had immediately been able to recognise and categorise her experience. After the diagnosis, Kate was encouraged to confront the condition, and do everything she could to overcome the symptoms. Kate had fortunately recovered from the condition, and had not experienced overwhelming symptoms for 10 years at the time of our interview. She explained that,

> You know, my mom said to me- and obviously my mom, my parents were a big motivator - and they said "look you can either just lie down and take it and be sick and sorry for yourself and not do anything with your life… or you can fight it". You don't have to be sick. It's not like someone gave me a blood test and said "here you go, you've got fibromyalgia and it's in your bloodstream", do you know what I mean? It's like you can do this. They used to force me to go to... they used to force me to do everything. And thank goodness because you do need that motivation.

Both the perceptions Kate held about the condition and its effects, as well as the control she had over the experience, were influenced directly by the attitude her parents instilled within in (Salmon and Hall, 2003; Skuladottir and Halldorsdottir, 2011). In shifting her self-image from being sick and incapable, to empowered and with choices, it was evident that Kate's parents had played an important role in influencing this process. In providing Kate with the social capital to overcome her condition and manage the symptoms until they were no longer a factor in her health schema, her parents had a tangible and powerful impact on her experience of fibromyalgia (Giordano and Lindstrom, 2010). By firstly acknowledging her symptoms as needing attention, and then taking her to a practitioner who was capable of diagnosing her, Kate's course with fibromyalgia was changed by the involvement and intervention of her parents. By allowing her to both be incredibly ill (in the fact that Kate's parents gave her sickness credence), and encouraging her to do everything possible to get better, Kate was able to tackle her experience of fibromyalgia in a supportive environment, and eventually she recovered (Bendelow, 2009).

Social insensitivity

Another participant who had largely recovered from her symptoms at the time of our interview was Alison. She also had a lot of support from her mother, as well as from her boyfriend. While her symptoms were less severe, she often experienced "flare-ups", and she noted the critical difference felt in her mother and boyfriend's attitude to her condition, compared to her father's opinion of her illness. Like Kate, Alison could attribute the positive attitude she held in relation to her health to her mother. She noted that,

> I think I've also… I've got very… a very good coping mechanism, I suppose, in my life because… they come from my mom… 'cause she also, whatever comes her way she just deals with it and then moves on. And I think that's helped me because whenever anything came up around to my life then I'd just be like, ok I'm going to deal with it now, finish, and then move on. Instead of having all these things inside and not dealing with them and then it comes out in a bad way, in your work or in your personal life. Or with your family. Like I said, it's not worth it to be like that and I think because I have… I can cope with a lot of things.

Alison explained that interacting with her father around her illness was tougher, as he had a different attitude to the condition from her mother. Alison's medical aid was previously paid for by her father, which also strained their relationship when dealing with her fibromyalgia (Issner et al, 2012). Alison acknowledged that her desire to work hard and succeed was heavily influenced by her father's perceptions and standards, but she found discussing her illness with him challenging. She related the following encounter in her interview,

> So when it comes to like my varsity work, my dad is very strict. So if like I don't do well on a test he's like, "why… and have you not been working hard enough?". But also he never studied… he doesn't have a degree but he worked his way up from the bottom when he was younger. So I appreciate that but he also doesn't understand the pressures when you're studying. But I know I can't tell him, "ah no, I'm all pressured and that's why I'm now doing badly". 'Cause it's not just that, it's also I have to work hard. And because he's pushed me, it's also making me want to work harder. So it's a good thing. But I'd like him to just be like, "well done", you know, once in a while. But that's him. So when I told him… 'cause he was saying, you know, "why are you always tired and you're sick" and he's like, "it's bad". 'Cause he was paying for my medical aid. And he was like, "it's run out". He's like, "why? Why are you so sick?". And when my doctor told me what it was and like he gave me articles and I took them to my dad, and I said "This is what's wrong with me". And he was like, "ah ok…" and he read through it. I still don't think he was… really understood what it was, or that he… really believed it's what it was but… like he knows. But I just… I dunno, as much as I… I can't explain anymore than what I had given to you, you know. And… now that I'm on my medical aid like… he doesn't really have a say anymore about how much I spend and things like that. So I think that also had an impact… on it… but like if he doesn't want to accept that that's what's wrong with me then… you know, I can't do anything more about that.

Having to repeatedly explain and convince her father that what she was sick with was medically recognised was complicated by the range of symptoms and manifestations she experienced (Barker, 2011). Her fibromyalgia was an underlying component of her illness experience, as she also had chronic sinusitis, migraines and IBS. This led to high healthcare utilisation with frequent visits to the doctor, but also an inability to explain the totality and connections between her conditions (Sauer et al, 2011). What this means is that in telling her father that she had fibromyalgia, she encountered barriers in acceptance from him. Part of this

was related to the fact that she could not concretely and definitively explain the forms and nature of her condition.

As a result, Alison struggled to garner support from her father in the form of acceptance and understanding for her condition, and the challenges she faced in living with it. Her incident with her father was similar to those described by Werner and Malterud (2003), who also looked at women's experiences of fibromyalgia. In Werner and Malterud's (2003) study, women who felt unsupported by their families also perceived their symptoms as more overwhelming than those who were able to rely on their social network for care and understanding. This is also indicative of the relationship between being believed medically, which enables the patient to take their condition seriously, and therefore find it possible to get support from those they interact with in their private lives.

Shreela explained this complexity in noting that the nature of the condition made it hard to get consideration from others, not just in relation to fibromyalgia. Fibromyalgia usually appears alongside a host of other conditions that lead to the individual being in a state of "hypertension of the central nervous system" (Meyer, 2012). This means that many things, such as noise, light and smell, trigger symptoms. Being able to tell others what was going on, and what was needed, and drawing support rather than suspicion and derision from others, was a task for people in this study, and was often something they could not effectively do. The fluctuations in the appearance and disappearance of symptoms presented additional opportunities for scepticism to appear from the people surrounding the individual with fibromyalgia.

Shreela had also mostly recovered, and was managing her fibromyalgia very well. She explained the difficulties faced in getting support in her workplace, and from friends, in accommodating her condition when it was still relatively overwhelming. She described how,

> **Shreela:** People get impatient with you. Because…uh… well you were walking last week… you know… how come you can't get out of bed today? Uh… you constantly have to explain… um… um… uh…. They kind of… "well what is that?" you know… when you say,

"I was diagnosed with fibromyalgia…" um… so… generally… social insensitivity, and not only to fibromyalgia.

SC: To illness generally.

Shreela: To illness generally. Even to… idiosyncrasies. You know… um… social insensitivities just in terms of how one occupies space with other people… for example, I… I still am sensitive to noise… but I was extremely sensitive to noise in those 11 years. Um… and I had a neighbour in my office at [previous workplace], in my corridor… who… would bang his office door, you know, so that these… what do you call, these dry walls would literally shake. Um… My friend would want me to go to clubs with him. And I couldn't bear the loud music, you know… and the… the vibration of the music through the floor into the body… actually triggers pain… you know… so all of those kinds of things… just a [sense of] not willing to understand that my world and my body works differently to yours. And that… I really don't mind if you go to the club on your own, please just don't beg me to come with you. Because… it is jarring on me. So… those sorts of, you know… social… insensitivities and insensitivities to the being of other… um… is what… prevents me from sharing it with just anybody.

Shreela was extremely protective of her diagnosis, was reluctant to share it with others, and was selective about who she could rely on support from (Travers and Lawler, 2008). As she had experienced a lack of accommodation because people could not comprehend the all-encompassing and variant nature of her fibromyalgia, Shreela was unwilling to open herself up to scepticism from others, and so was unwilling to disclose her diagnosis to people she did not trust (Scrambler, 2009; Gilson, 2003). The use of strategic social capital had allowed her to enhance her health, and recover from her fibromyalgia. This was due to the fact that she placed importance and dependence on people she felt would be understanding and supportive, rather than those who had previously treated her and her condition with disbelief (Skuladottir and Halldorsdottir, 2011). This relates to the earlier theme of the difficulties faced with the double delegitimation associated with contested conditions (Richardson, 2005). Having found medical acceptance and support, there is then a secondary challenge of finding acceptance and belief from the people that the person with fibromyalgia frequently interacts with - at work, at home and in social situations. The stigmatising effect of people's inability to support those with incomprehensible conditions was evident in many of the

narratives, and is acknowledged here for the tangible and profound effect it has on the person living with fibromyalgia.

Many of the younger participants experienced difficulties in engaging with their parents, and other family members, around the unpredictable and chronic nature of their symptoms. They were also baffled particularly when parents who had chronic conditions too were perceived to be unsupportive and unhelpful (Bogenschneider and Pallock, 2008; López-Martínez et al, 2008). Chloe's relationship with her mother had, for a time, been tarnished by an inability to interact around her illness. She explained that her mother's attitude mystified her and elaborated that,

> **Chloe:** She really just…
>
> **SC:** Well what does it manifest itself as?
>
> **Chloe:** Uh… like almost aggression… I guess it's like a mother thing, if your children are not doing well in one thing you can either be super-sympathetic or you can react to it… um, out of anger because there's that protective thing. I don't understand it, I really don't. But, she… Ja, she seems to get angry with me when I'm in pain or… like super tired. And it's not always like… "ag[14], man up", it's just like, when I can't get an answer out of her, what it's about, what's going through her head.

Having moved out of home, Chloe found that her relationship with her mother had vastly improved, and they were able to relate better about her fibromyalgia than before. In the course of the interview, Chloe explained her family attitude to contested conditions, as well as the contradictions found in her mother's ability to comprehend parts of fibromyalgia experience, but simultaneously snub other components of the condition. In our interview we noted that,

> **SC:** You guys [Chloe and her mother] have a very close relationship
>
> **Chloe:** Ja.

[14] "Ag" is an Afrikaans expression, commonly used to denote derision

SC: So that must be quite challenging to negotiate through. That she doesn't… give you what you would want or need in that moment. Because I'm assuming you don't want aggression.

Chloe: Mmm. Ja.

SC: And what, do you think that's because she wants to protect you and for you to not be in pain and cannot understand it herself so cannot …?

Chloe: I think that… that is part of it, like, I think my whole family has that trait. If you don't understand it then you treat it… hostile…

SC: With hostility?

Chloe: Ja.

SC: So what, reject it if you don't get it.

Chloe: Yes. Ja. Like she has arthritis and so I think she gets half way to understanding it and then she can't relate [to] the other half… almost worse because she can relate for the one half. And it just… I don't know. It's weird. It was very painful… metaphorically to live with her for the past while.

Chloe characterised her family as being suspicious of things that could not be explained or clearly understood. She noted that the aggression felt from her mother was an attitude she had encountered with other family members, and was challenging for her (Campbell et al, 2011). She also found it strange that her mother struggled to be sympathetic to Chloe's experience of fibromyalgia, in light of the fact that her mother lived with arthritis. This was similar to the interactions recounted by Teresa, whose mother also had arthritis. Teresa found it difficult to deal with her family's frequent teasing and derision of her illness and the ever-present, irresolvable nature of her pain. She explained that her family perceived her as a "complainer" and,

Teresa: My siblings and my… my dad loves teasing me about it… But… I mean you should have seen him when he had tennis elbow, he was pathetic about it. And I was like, "that's what I have every day!". Um, no my mom's got arthritis so she knows what it's like, but at the same time she's kind of like, "you know, you have it, deal with it"… sort of… no, no, they sound really mean but she's got arthritis, really bad arthritis in her hands but she's a violinist, you know that's what she uses. She has to go and have huge, giant needle injections into her

> knuckles and stuff like that. And I think… she knows that there's nothing really that I can do about my… and she's sympathetic to it but at the same time… there isn't anything I can do, there isn't anything they can do… so… really it's just… you can say that it's sore and…
>
> SC: And then do you feel like you have to say nothing more about it?
>
> Teresa: Ja… unless… also there's just no point… she doesn't know what will make it better, you know?

In this part of her narrative, Teresa was expressing her inability to draw on support from her family, because there was a lack of comprehension about the nature of her fibromyalgia. Her family was unable to move past the fact that the pain and exhaustion were not treatable, and so inevitably they stigmatised her and were unsympathetic (Neilson, 2010). Interestingly, she also showed how her father was not able to relate to Teresa, despite dealing with a painful condition like tennis elbow, and rather than being supportive, he teased her about her complaints of pain. Contrastingly her mother, whose arthritis was depicted as more severe and disabling for her than Teresa's fibromyalgia, was given sympathy on account of the effect her condition had on her mother's ability to work as a violinist. Teresa's mother's was able to relate to her daughter's experience (given the overlapping symptomology of fibromyalgia and arthritis), and therefore offer support.

However, the capacity to be sympathetic was limited when the complaint was enduring and nothing could be done about it, as was the case of Teresa's untreatable fibromyalgia. This disjuncture between being able to understand the experience, and not being fully supportive of the person because there was nothing that could be done for them, echoes the broader issue of legitimacy of experience that has been discussed extensively in this thesis (Jackson, 2005). Burke and Valeras (2008) note the combined difficulty of a condition that is invisible and which predominantly affects women, and they attribute this to the discrediting experience of fibromyalgia. While gender roles and positions can affect the capacity of people with fibromyalgia to articulate their experience in medical consultations and social life, the people involved in my study found discriminating and discrediting attitudes from both men and women. This meant that stigmatising perceptions and behaviour emanated from people on the basis of factors other than gender, and included intimacy of the relationship, proximity to the ill person, ability to articulate the experience, and willingness to accommodate the person. This is discussed in greater detail throughout this chapter.

Teresa speculated that her parents' lack of understanding, and her feelings of being unsupported in her experience of fibromyalgia, was related to the roles that parents and children enact in relation to illness behaviour (Ell, 1996; Percheski and Bzostek, 2013). Part of familial support for chronic illness, and the difficulties faced in drawing on it effectively, lies in the inability of families to offer advice and treatments that could alleviate symptoms (Lupton, 2003). Teresa explained this clearly in saying that she was discouraged from speaking about her pain to her mother, as there was nothing to be done about it. In our interview it was related that,

> **SC:** And then do you feel like you have to say nothing more about it?
>
> **Teresa:** Ja… unless… also there's just no point… she doesn't know what will make it better, you know…
>
> **SC:** So what? Complaining is for a very particular purpose which is to fix it?
>
> **Teresa:** Ja… I guess… my family likes teasing people, so I think if you complain a lot you're just going to get teased about it so…
>
> **SC:** So… you don't like being teased in that way?
>
> **Teresa:** It's just a bit frustrating, 'cause like, you know, it's actually sore. If you… I feel like… if they actually had to deal with it then it wouldn't be quite so much of a joke as it is, you know… with me having to…
>
> **SC:** So you feel like they don't take it seriously?
>
> **Teresa:** Ja, because its… what is it, you know? It's kind of nothing… especially now after the last person I went to, it's kind of… "What is it really?" So I mean… and now also, since I've been in Pietermaritzburg, just always being sick, it's just kind of like… [They say] "You're just always sick, there's just always something wrong", and it has been like that, that there's always something wrong.

She explained that having moved away from home, in Johannesburg, to Pietermaritzburg had increased the amount of teasing from her family, because her pain and illnesses were not as apparent and in their immediate experience as it would be otherwise. In this part of her narrative, she also noted that, following a discrediting encounter with a practitioner in

Pietermaritzburg, coping with the perception of her pain as less legitimate and real was harder (Arnold et al, 2008). Her family's perception of the condition was disheartening and frustrating. The stigmatising effects of her family's attitudes to her illness had resulted in Teresa feeling like she was not supported or understood by her family, an experience that was related by other participants in their narratives (Åsbring and Närvänen, 2002). Teresa had encountered both felt and enacted stigma from her family, as her identity as a legitimately ill person was undermined, and she frequently received derision rather than sympathy from them (Scrambler, 2009).

In this context of low levels of parental support, many participants turned to peers and partners who were assistive in confronting the unpredictable and elusive nature of fibromyalgia. In presenting information, referrals to practitioners, and emotional support for the person living with the condition, peers and partners were instrumental in the individual's capacity to cope with a confusing and challenging illness experience (Campbell et al, 2011). Peers and partners provided practical care, while taking on domestic duties which could not be managed by the ill person, and afforded them understanding of the experience as it manifested, rather than how illness is expected to unfold them to be "sick" (Oliver et al, 2001). Where partners were perceived to be derisive and unsupportive of the person with fibromyalgia, there was also damage done to the ability of the individual to embody an illness identity, which would have enabled them to manage the condition effectively (Åsbring and Närvänen, 2002).

Specifically when people were seen to be unsympathetic to the nature and severity of the participant's fibromyalgia experience, there were also feelings of despair, rejection, and discouragement experienced by the individual. Teresa's family was largely unable to be sympathetic to her experience of fibromyalgia, because they misinterpreted the meanings of her conditions, and cast her as "always sick" and almost wilfully unable to get better (Timmermans and Almeling, 2009). Additionally, because she came from a large family, healthcare provision through medical aid insurance was limited for Teresa, which in turn discouraged her from consulting with practitioners as often she might have needed to. Her family did not have medical aid, and Teresa and her family struggled to pay for consultation and treatment costs outside of medical aid rates (Percheski and Bzostek, 2013).

In this situation, she utilised self-care strategies of attempting to avoid environments that aggravated her symptoms, and taking vitamins and supplements, as well as eating in line with a healthier diet (Travers and Lawler, 2008). She explained that,

> Um… my mom always tells me to gargle with salt water and I just can't do it. I just can't do it. I gargle with Dispirin and that's sometimes helpful. And then I eat oranges and I stay in bed. That's really… I take Farina which are homeopathic drops for post-nasal drip. And it kind of works a bit. But I mean then, last year there was a time when… I was sick and I thought… it had been a little bit worse, it was a bit more fluey, you know, had like night sweats and everything aching and I had a bath, I got into the bath and then my phone rang I got out of my bath and I just took two steps and then I sort of passed out a little bit. Not completely, I sort of, fell down. I didn't lose consciousness, but I just kind of… ja. It was more like fainting. Ja, ja. Really dizzy, you sort of faint but then… you're sort of conscious, but you can't move yourself.

This incident that she related was exacerbated by the fact that, as a young student living away from home, she was not in an optimally supportive environment, both in terms of getting help from the people she was living with, and at the point of accessing medical care. She went on to describe how,

> The girl who lived in the next room to me, I was living in a digs then, she saw me and… she called the other people and they carried me back into my bed and then they… called the doctor and made an appointment for me and put me in a taxi. Actually they didn't really care, I had to make the appointment, I had to get myself in the taxi but whatever… I went there and the doctor said that I actually had really severe bronchitis and she wanted to send me to hospital because she said it was probably going to turn into pneumonia. I was like, "please don't take me to hospital". And I was like, "I also can't afford to go to hospital". And she said, "you can't go back to digs, you can't go to a place where someone's not going to look after you". So…. My aunt came because my aunt lives on the other side of Pietermaritzburg and she had to leave school, the doctor called her… she came to pick me up. We had to go, a thousand Rands worth of antibiotics and a humidifier with certain things that you had to put in that humidifier that you would rather had not been in. So you know, I had this mask, I was lying in bed, and sort of felt like Darth Vader, you know, breathing … [laughter]. Ja, so I was her house for like a week.

Teresa did not feel encouraged to talk to her family about her pain and fibromyalgia on a regular basis, as there was the perception that there was nothing to be done, and she was therefore complaining unnecessarily. Beyond that stigmatising interaction, Teresa knew that her healthcare utilisation was unaffordable for her family, and thus she put off medical consultation for as long as possible. This meant that by the time she got to the doctor, she was seriously ill (Lonardi, 2007; Sanderson et al, 2011). This relates to an earlier theme of the restrictions of prohibitively costly medical care and discouragement that occurs in terms of seeking help early in an illness experience (Percheski and Bzostek, 2013). Being away from her family was additionally challenging, as there was practically no-one to notice and care for Teresa, which resulted in her having to be almost hospitalised before anyone intervened. Feeling unsupported and misunderstood directly drove people with fibromyalgia to push harder against the limits of their condition, and this often resulted in a worsening of their symptoms.

Claire was divorced but was seeing someone new, and she contrasted the approaches of her two partners to her condition. Her ex-husband had been continually sceptical of the severity of her symptoms and her ability to overcome them. This discrediting experience had meant that Claire was reluctant to give in to her symptoms until she literally collapsed, and she found it difficult to adhere to the notion of resting as part of her treatment as a result (Morris et al, 2011). Claire related how acceptance for reality of fibromyalgia was challenging for her, as she had faced derision and scepticism from many people in her social network around the vague aetiology, including her parents and her ex-husband (Jutel and Nettleton, 2011; Issner et al, 2012).

Connie faced similar difficulties with her husband, who had only known her with fibromyalgia. During a crisis where Connie's son was hospitalised, following fever convulsions, she reflected in her narrative of the event, and how unhelpful her husband had been. She also discussed the continually discrediting attitude towards her fibromyalgia that she experienced from him and her mother-in-law. She described how,

> [Her son] had convulsions in Glynwood, in Roseacres, so I can take him anywhere but his paediatrician is in Linmed. I was half way to Roseacres, stuck in traffic. I made a U-turn straight to Benoni, taking him to the Linmed. When I got there, I dropped my husband off, I parked the car, I walked in with my stiff neck, and here is my husband sitting with my son on his lap, and I said to him "and why you sitting there?". He's saying "no they told me I must take a seat and queue". And I picked my son up and I walked in and they said "Mevrou[15]", we said. I said, "listen this child has a very high fever, I want someone to take care of him now. I don't care then you make a space even if you have to open a table you make a space for him now. I'm not going to let him have another one". You know, what they did, they took the quarters of the doctors where they sleep and they gave that bed to my son. And I came out and I went onto the thing, the couch, and I just started to cry. I just cried. You know, it's all these things and you're already so sore and you have to take the child from your husband's arms, you just have to sort of force your way in. You would sometimes expect the husband [to do] that and not a mother to do that. But you know, I had to pick him up and I had to do this. And this nurse came in and she said to me, "you've got a bad neck" and I said "yes, thank you I know that. But that's not important. My son is important".

Having got her son admitted to hospital, Connie was reflecting on how stressful the experience was for her, and the consequences for her worsened state of health (Ablin et al, 2012). She related that,

> **Connie:** I already have a stiff neck, then you have to go through something emotional like that. This is a recipe for putting you in hospital. The next morning he [her son] went for CT scans and EEG and stuff like that, for all sorts of stuff. That night I took my in-laws to the hospital. And I've a Portuguese mother in-law. Nothing is good enough. She criticises the doctors, the nurses, from the medical aid that you've got, from you being a parent. I went in there I bathed the child, I came back, my mother in law said to me "are you fine?" I said "I'm not feeling well. I don't know what it is but I'm not feeling well". I was as pale as this bottle. She left and a very bad feeling came over me from my feet just up like this. And I was cold. I had goose bumps. I went and bathed. The water was hurting my skin. The facecloth, it felt like I was scrapping off my skin. It was hurting, the clothes was hurting me. My nightie was hurting me, my bra. Everything was hurting me. The bed felt like I was sleeping on pins. It was bad. Here my body was so sore it felt like a very bad flu, something that was coming down on me. That night every half an hour I would drink a glass of water to 500 ml of water.

[15] "Mevrou" is Afrikaans for "Madam" or "Mrs"

I don't know how much water I had. By six thirty I was up and I wake my husband up and I said to him "James, wake up. I'm sick. I'm going to the doctor". He says, "six thirty [on] Sunday morning?" I said, "I'm going to the doctor". I said to him "you must get up and take my bag off". He says "for what?" I said "I'm going to the doctor". He says "Ag, you can wait. The doctors only come in at eight or nine". My daughter was up. I went to bath again, 'cause I'm cold, I'm shivering. I can't explain it to people but it's a bad feeling, it's just a bad, bad, bad feeling. I eventually took a bag and I put some stuff for my son in, and I put my stuff in for myself.

SC: Was your son still in hospital?

Connie: He's still in hospital. Being treated for the fever convulsions. And I got here to this doctor and she said to me, "you have no idea how sick you are. You've got not only fibromyalgia but you are having emotional shock on top of this sore neck of the fibromyalgia. Plus you are coming down with a very bad flu symptom that has now attacked your entire nervous system. You are so sick. You are being admitted to hospital". And this was my first time being in hospital for a neck. I drive to Linmed, I just looked at my son. I said "listen Mommy is going to the other hospital". Now you must know the family [is] having the son in Linmed and I'm admitted to Glynwood because there is no doctor, no orthopaedic surgeon there at Glynwood hospital. And I'm just phoning my parents, they're just coming from church, letting them know I'm going there. Phoning my husband. I'm going there. You know he's a very casual person. "What's this? This is nothing, you know, I can't see that you're sick" [he says].

Connie's husband's inability to comprehend the severity of her condition in this instance was indicative of the complications faced in living with someone with a chronic illness. Soreness, stiffness, pain, and exhaustion become normalised in everyday experience, and recognising when a state of health has worsened, dramatically or subtly, is difficult for the person with the condition to communicate (Sim and Madden, 2008; Richardson, 2005). Connie's husband was unsympathetic in the face of her apparent illness, because he could not see the symptoms as out of the ordinary in the context of normalised fibromyalgia. The symptoms themselves were largely subjective, individually experienced and, in many senses, invisible (Madden and Sim, 2006).

In not being able to see that she was "sick" led to Connie's husband believing that she was not in fact severely ill. This was despite the fact that she was critically ill, to the point that she was hospitalised, and diagnosed with having a nervous breakdown in addition to having fibromyalgia. This shows the onset and exacerbation of illness that occurs in and amongst other events (Nettleton, 2006b). The event of her son's health crisis brought many tensions in Connie's relationship with her husband to the surface, in that she felt his inability to understand her experience. He was also unwilling to shoulder any of the responsibilities, as she felt he should, in terms of ensuring her son got immediate medical attention at the hospital.

Another aspect of the findings in relation to social support that emerged was that many of the younger participants of the study cohort only had access to medical treatments, practitioners, and facilities through the medical aid insurance held by their parents. The differences in availability of medical insurance reflected what Percheski and Bzostek (2013) asserted in terms of familial access and healthcare utilisation. Over and above providing care and support to someone living with a chronic condition, families were also sites of access to healthcare, either by supplementing medical expenditure of their dependants through insurance, or by paying out-of-pocket for necessary consultations and treatments. Karen accessed medical aid with the support and assistance of her parents, while Frances' medical aid was provided by her husband's workplace. In the latter instance, the fact that Frances was on that company medical aid had resulted in unlimited access to healthcare for her, as the scheme covered all her medical expenses. Frances was able to draw on resources because of her husband's position and workplace access to medical insurance, which in turn showed how her social capital afforded her better healthcare (Giordano and Lindstrom, 2010).

She did contextualise her experience of interacting with medical aid around her fibromyalgia by the fact that her treatment largely occurred in the mid 1990s, before the advent of highly complicated, bureaucratized medical categorisation and privatization of healthcare in SA (McIntyre et al, 2007; Gilson, 2003). The converse occurs when a lack of family resources means the individual is without medical aid, and therefore has to alter the way in which they interact with healthcare providers, because frequent consultation and treatments prescribed are prohibitively costly. This was the case for Chloe, Jenna and Teresa, all of whom were

young and unemployed, and therefore still highly dependent on their families for fiscal support and practical care in managing their fibromyalgia.

Claire's relationship with her ex-husband was contrasted by other participants' narratives, where partners and peers were able to offer tailored social support that met their needs, and allowed them to move through their illness experience with fibromyalgia in relative comfort. With her new partner, however, Claire felt supported, and was amazed that he did not question the vague nature of the diagnosis, or the multiplicity and unpredictability of the symptoms she experienced. She explained that,

> Um and I think it feels hard to… to allow myself that and it also feels hard that other people would just accept it. Um… so like you know, I think there was a Sunday where I actually just slept the whole day. My boyfriend and I had slept in late and then he went off to go do some stuff and then I sent him a message… [Saying] "I just had this really disastrous day; I just like slept all day". And he said, "well that's great. You know, you needed the rest." And then in my head thinking, "he must just think that like I'm a total… kind of… lazy is the word that comes to mind… I'm just like a bit of a slacker you know"…

Claire struggled to overcome the feelings that had resulted from her parents and ex-husband's stigmatizing remarks about the nature of her condition. In encountering her new partner's attitude of acceptance of her condition, Claire was able to begin to view her illness in a new light, and therefore was also able to eventually shift her perception of rest as necessary, rather than as a sign of "laziness" or "slacking" (Jackson, 2005; Åsbring and Närvänen, 2002).

As discussed by Gage (2013), people with fibromyalgia were also important sources of social support for others living with the condition. Claire, Connie and Helena had all been referred to specialists who could diagnose them with the condition, by people in their social network who knew about fibromyalgia, or were living with it themselves. In turn Claire, Frances, Connie, Helena and Zainab had all provided advice and emotional support for those who were recently diagnosed, and still learning to live with fibromyalgia (Mazanderani et al, 2012; Skuladottir and Halldorsdottir, 2011). Therefore, at the point of finding a recognising and diagnosing practitioner, and afterwards in learning to cope with the demands of the

condition, people with fibromyalgia drew on support and information from experientially similar others (Barker, 2008). Subsequently, they were able to fulfil that role for others who were newly encountering the condition (Gage, 2013).

One instance where encountering experientially similar others was enormously helpful to a participant was found in Frances' narrative, where she spoke about attending a pain clinic in Cape Town. She explained that,

> **Frances**: The fascinating thing wasn't necessarily what they [at the pain clinic] did for your pain, it was watching people and how they dealt with theirs. And you had the absolute miseries and you had the get up and go's and you had the "well there's nothing I can do about it" jobs. But to watch other people's reaction to it… apart from taking yourself out of yourself… looking at it from a different perspective, it was just fascinating. Absolutely fascinating. From a whole psychological point of view. And I think… it helped me tremendously just to… focus on which way was the way to go, to deal with it. It was very, very interesting. So I would recommend it to anyone who has a chronic pain problem. Just from the… finding out ways to cope with it. You have to be taught how to cope with it.
>
> **SC:** And you've assisted other people to learn how to cope with it. What do you say as strategies, aside from accepting it and it's there and it needs dealing with.
>
> **Frances:** Well first of all I think you have to have a really good rapport with whosoever is dealing with you. You have to have an understanding, you have to trust the person who's dealing with it… you have to take as active a role as possible in… managing the condition. Because you do have to be empowered with it. You can't just sit back and… take whatever they say. You have to have decision making in it. You have to discover your own limitations and accept those. But… at the same time you have to push the boundaries. You can't sit and… accept that for the rest of your life. You have to… in acceptance, you have to stop fighting with yourself over it. But you have to live on. I think you have to find ways to keep yourself busy. Because there's nothing worse than sitting and thinking about it… my "busyness" started with taking up embroidery again. 'Cause I find, and I think most people would, that you can cut out a lot of your pain perception by concentrating on something else. And pain, if you concentrated on it, only gets worse… there is no doubt about that. I mean if I sit and think about how much my back's hurting… it hurts a lot more. That's… just the way your mind works. I mean, there is always a modicum of mind over matter. And I think you have to capitalise on that. And… you have to be positive about it. You have to know that, yip, ok,

your body's let you down but there's a lot more you can do around that. But ja… and you have to talk about it. You have to be open about it… it's a problem but it's a problem … like you deal with your blood pressure by taking a tablet… deal with your cholesterol by taking a tablet. And if it takes medication to help you deal with it, so you will. There's no stigma in taking an anti-depressant if it makes… helps you sleep at night, because if you can sleep at night you can deal with pain during the day. If you're awake all night there's no way you're going to cope the next day.

Frances' above narrative correlated with the strategies of success used by many of the participants who had been living with fibromyalgia for a number of years, and largely understood their symptoms, the meanings of the condition and how to manage it. Part of offering and drawing social support to and from experientially similar others, was the normalisation of symptoms, behaviours, and attitudes to treatments which proved an important part of coping with fibromyalgia. This links to Gage (2013) and Campbell et al's (2011) explanations of the role of social networks, in enacting health behaviour, and gaining knowledge in relation to illness.

Zainab explained how she had given advice to a colleague and a friend when they had been recently diagnosed. The point where she was in her illness career (having lived with fibromyalgia for more than 20 years) allowed her emotional distance from the meanings of the condition. She was also able to contextualise the condition, having realised the chronicity of the experience and the strategies that had worked for Zainab. This process was not without complication however, as Zainab was unsure that her advice was matched to her friend's specific manifestation of pain. She explained that,

Zainab: Well its… it's like swim or sink kind of thing… especially if you want to keep… I think if people are pushed, because even with my friend… although she claims… I mean how debilitating it is and everything… but when she needs to do something then she can do it. You know it's not like she can't… and that's also what I found is… even… like you think, oh well… I'm so sick I can't lift this thing but you go and lift the thing up and nothing happens to you, you know? So you…

SC: So it's also about your attitude towards it?

Zainab: Ja and its not… it's more not being afraid… you have to… you see, that's where I'm also a bit worried, is that sometimes, maybe this is me… I'm saying maybe this is me, maybe this is what my condition is, where I can do all that… but sometimes I say it to, like even my friend, I said "you know what, I promise you, if you go and lift something heavy, nothing's going to happen to you. If you do it the right way, nothing's going to happen to you"… exactly like the next person… if you do it the wrong way, lift something the wrong way and you know you might… hurt…

SC: It's not because of your fibromyalgia it's because

Zainab: It's because… ja… it's that… imbalance or whatever it is… ja… but then afterwards I think, you know am I giving the right… maybe… her pain is different …

Gaining or offering support to experientially similar others produced an interesting reaction, when viewing the presence and utilisation of online support groups in the process of seeking information and knowledge about fibromyalgia, and possible routes of treatment. Almost all participants had turned to the internet and other media sources, at some point, to make sense of their symptoms and the meaning of fibromyalgia, as well as ways to absorb the experience and demands of the condition into one's life (Price and Walker, 2013; Lupton, 2013; Tang and Ng, 2006; van Uden-Kraan et al, 2009). Many had encountered online support groups, and despite the prevalence of the personal telling of fibromyalgia through blogs and other forum, the narratives contained in these e-spaces were unhelpful and unpopular for my participants. Some felt that they could relate to the experiences being described, but eventually they tired of the overbearing "complaining" tone of the narratives that, in light of trying to remain hopeful and positive about their future, was not useful in the participants' attempts to adapt to having fibromyalgia in their lives (Morris et al, 2011).

Popular perceptions of fibromyalgia in South African media

Media content analysis was not a primary means of data collection for this study, but it was important to see how information about the condition circulated at the most general level of the media in SA. This was due to the fact that knowledge about fibromyalgia is continually revised and updated as new modalities of understanding and treating the condition emerge.

Information surrounding elusive conditions like fibromyalgia in medical discourse is disseminated unevenly. Practice and treatment recommendations reach patients only through the right combination of a recognising practitioner, articulate patients and functional, accessible health services. In this environment, understanding the range of information and particularly the content thereof becomes a critical way of assessing the successes, failures and opportunities found in diagnosing and responding to fibromyalgia as a chronic condition.

In order to clarify the perspectives offered by the participants of this study through their narratives in terms of their use of media to make meaning of their experience of fibromyalgia, a brief media content analysis was conducted. As there were more prevalent and influential sources of information that had a greater impact on the experience of those living with fibromyalgia in the management of their condition, media is viewed as an additional layer of the picture as another piece of the puzzle. Within the narratives, the participants spoke generally about their searching practices and purposes, and the information they garnered fell broadly into the following categories:

- Symptoms and labels
- Descriptions and explanations
- Treatments and lifestyle adjustments
- Social support

The media was influential for the participants but this manifested in diverse and interesting ways. For some, the diagnosis of fibromyalgia only came once they had encountered the label online. Others found that the vague explanation offered by their diagnosing practitioner motivated them to seek out further understandings of fibromyalgia on media platforms. Almost all participants had investigated possible routes of treatment and some had experienced successes while others found that the suggested remedies were entirely useless.

Interestingly, in spite of the prevalence of this type of website, many of the participants found the overall tone of online support groups to be unappealing as many of the sites were engaged in "catastrophising" the experience. This last point is markedly different from many authors who find e-spaces to be a critical component of addressing contested conditions as there is a

community of experientially similar others that are directly and easily accessible (Conrad and Stults, 2010). This could be a quirk of the study design used in my research, as narrative interviews, rather that internet interactions and content, was the primary means of drawing out data for analysis. It also could be related to the point at which I was interviewing participants, as an unintentional criterion for inclusion was "readiness" to talk, meaning the participants had gained a certain level of distance from the apex of their fibromyalgia experience. This meant that they were possibly out of the phase of "searching" for answers and the process of directly making meaning of their experience. Rather, they were adjusting and learning to cope with their condition. Nevertheless, there is no doubt that the media had an impact on their experiences during this course of their illness careers.

The media content analysis undertaken here looked at internet news articles from SA databases and covered the time span of 2000-2014. News articles were specifically used because they represent the most general, accessible level of information, where knowledge circulates among the broader population. Like with the academic literature, there is little mention of patient experience, which again highlights the value of the study undertaken here in offering perspectives drawn from the narratives of those living with an elusive, contested chronic pain condition like fibromyalgia. Participants of the study would have most certainly encountered information about fibromyalgia from a range of contexts and countries. However, the analysis included here looked particularly at articles that appeared in SA news publications to get a sense of what information people living in SA would have been exposed to in relation to fibromyalgia at the most general level (Paralikar et al, 2011). Confining myself to a limited analysis of media in SA only was also a practical decision since a more comprehensive analysis is beyond the scope of this study. Having said this, a detailed media content analysis of fibromyalgia perception in SA could be a topic of interest for future research inspired by this study.

Searches were conducted on the "Mail & Guardian" and the "IOL" online sites using the search term "fibromyalgia". This generated a total of 28 news articles that spanned 15 years of published information. The majority (15) of the articles were published in the years 2010-2013 with the fewest (4) articles being published between 2000 and 2005. This trend shows a stark contrast between the early presence of fibromyalgia as concept in SA media discourse

in the early 2000s and then a sharp and steady rise more recently as the label has attained more recognition and relative legitimacy within medical discourse. Kate, a participant in this study who had experienced fibromyalgia ten years ago, reflected on the change in availability of articles in the intervening period by commenting that, "Yes. Ten years ago there were like ten websites with it [fibromyalgia] on, so it wasn't like it was huge, it was like two blogs. I actually tried to look it up the other day and there was so much stuff. And people won't know which one [site] to go to". The overlap of the diagnosis from medical discourse into information that is easily and readily accessible through the media shows an important shift in the status and awareness of the diagnosis that contributes to making it medically and socially real.

Additionally, in being able to refer people to a platform like the media which is distinctive in its ability to convert complex information into relatable explanations, people with conditions such as fibromyalgia can draw on social support more easily (Cooper, 2002; Dumit, 2006; Barker, 2008). In this case study, the media and information found on the internet had a direct impact on the ability of some participants to come to terms with their diagnosis and the recognition of their symptoms. Furthermore, the media offered participants the means of treating and managing their condition and avenues for explaining their experience to others.

Most of the articles used mentioned fibromyalgia tangentially to other illness conditions, issues and concerns including other spectrum conditions, gender differentiation, and general symptoms of fatigue and explanations of new treatments for chronic diseases. This could be seen in "Dogs can tell when epilepsy strikes (Elkins, 2012.06.08); "Scorched tree poser for cellphone giant" (Bega, 2012.01.28); "Feeling burnt out?" (Grange, 2013.01.10); "Truth about male and female brains" (Hurst, 2013.04.23) and "Hope for Down Syndrome patients" (n.a. 2010.01.07). While many of the articles were reports that had been published in international papers, there were some local stories, which were of particular interest given the dearth of information about fibromyalgia in the SA context. One article detailed a court case between a large retailer and a person injured in one of their stores, who later developed fibromyalgia ("Woman awarded damages from Shoprite", n.a. 2012.02.02). The article explained the incident that led to the woman being diagnosed fibromyalgia and the court proceedings that resulted in a financial settlement for her. It also related the nature of her

condition, in the causes (an injury) and the manifestation (soreness and fatigue) as well as the impact on her life as a result of the incident.

The majority of the articles that directly spoke about fibromyalgia offered generalised explanations of the associated symptoms and discussed the uncertainty and contestation surrounding the condition, or made suggestions for treatments that could alleviate the pain and exhaustion being experienced. "A gluten-free diet changed my life" (Ord, 2012.06.05), "An enlightening treatment for arthritis" (Tarr, 2012.01.16), "Dr Darren's Thursday surgery" (Green, 2013.05.23) and "Reduce stress to avoid chronic fatigue" (Fox, 2006.11.04) all offered more concrete information relating specifically to the symptoms and features of fibromyalgia. In the consistent theme of "advice and treatment", these articles presented fibromyalgia as a condition (alongside others) that was challenging to address but there were routes and opportunities for overcoming symptoms.

People with fibromyalgia would have gone further in their internet searching, as they would have needed more information than these news articles offer. Having said this, the articles give a good sense of the broad themes in the range of information available online that refers to fibromyalgia. In creating a commonsense framework and understanding of fibromyalgia and the complexities involved, the media fulfils an important role for people with the condition to see the presence of the label in their everyday social environment. As Hilton and Hunt (2010: 1) note in their discussion of media representations of the 2009 swine flu epidemic, popular media and news stories "are often constructed to take one perspective or another to define which issues are viewed as important.

These perspectives or 'frames' influence what is included or excluded from stories and can misrepresent the scientific evidence… the priorities and decisions of policy-makers may also be influenced and altered, at least partly as a result of news representations". Presenting scientific, medical information and disseminating it through a platform as broad-reaching as the media means that the tensions, conflicts and dominant discourses on health-related matters are immediately accessible in the population. In getting information out quicker and by offering different avenues for accessing health knowledge, the media has had an important

impact on the perceptions of fibromyalgia, both for people living with the condition and those that surround them (Reilly, 1999).

Furthermore, in seeing the transition from previous debates about the existence and legitimacy of fibromyalgia through the articles through the articles “An open letter to the Medicines Control Council" by Jobson (2009.04.15) and “Life Offices’ Association defines disability" published on 2001.05.05, to the frequent use of the term in medical reporting, there is scope for understanding the credibility the condition has gained, most especially in the last 10 years. The ‘normalisation’ of the diagnosis into everyday health discourse (as evidenced by the slight increased presence of articles related to fibromyalgia available online) must have some impact on the de-stigmatization of fibromyalgia. This is due to the fact that general notions of the condition can be drawn on alongside medical explanations to describe the experience of largely invisible symptoms (Lonardi, 2007; Cohen et al, 2011).

As the themes of the articles reflect broader trends in media content with regards to fibromyalgia, this section has given a brief description of the media context in which the condition is discussed, explained, responded to and drawn on. This media content analysis has offered a general description of the types of media and the content thereof that people living with fibromyalgia continually draw upon along the paths of their illness career. Additionally, explanations for the increased presence of articles relating to fibromyalgia aetiology, treatment and experience in the last few years were presented in this section. This gives a basis for a general understanding of the forms of media content that people interviewed for this study may have encountered in their knowledge-seeking activities.

Trust in managing fibromyalgia

The development of trust between healthcare practitioners and their patients was articulated in two key ways by people living with fibromyalgia in SA. Firstly, the presence of a recognising attitude from the practitioner allowed the diagnosis of fibromyalgia to emerge in the interaction. This in turn legitimated the patient and their experience as medically real, and a sense of trust was further fostered when a patient continued to consult their practitioner, and

felt confident about their ability to manage the condition together (Glenton, 2003; Dumit, 2006). Secondly, trust and social capital could be seen to be utilised where patients require practitioner support to access further medical aid coverage for their chronic medications. Shreela moved to a new practitioner, and in developing a good working relationship with her doctor, she was able to effect support and access to medical aid coverage for her chronic medication (Åsbring and Närvänen, 2004). She explained that,

> So I… via Dr Ayeye, I connected with Vernisha Naidoo, who is a psychiatrist at Donald Gordon. Because I said to Dr Ayeye, could he please recommend me to someone… who can prescribe my chronic meds for me, but who also has knowledge of fibromyalgia. And he kind of looked around for a while, and he was the one who said to me, you know "most of the people I know who are knowledgeable about fibromyalgia are in Pretoria… so I just need a while". And then he recommended her, I went to see her… and uh… she's wonderful. She agreed to just hold me on the treatment programme that John [her previous practitioner] put me on.

This component is particularly important in relation to the study described in this thesis. This is due to the fact that ongoing management of fibromyalgia in this context required support, social capital, and trust between people living with the condition; their families and peers; and healthcare practitioners. This was demonstrated in Shreela's above narrative, where the ability to request recommendations, and receive support from practitioners who understood fibromyalgia, were able to treat her, and assist in negotiating with medical aid for chronic medication coverage, generated an atmosphere of collaboration and trust (Audulv et al, 2012). Where low support and social capital appeared, so too did worsened states of health for the people with the condition, as well as feelings of isolation and rejection as described in this chapter. For people who were able to rely on their families and peers, and practitioners, and had high levels of social capital, which were evident in the trust between the individual and these sources of support, better health outcomes were evident. The next and final chapter of this thesis offers a general discussion, conclusions and recommendations that emerged in this study.

GENERAL DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

In exploring and analysing how people living with fibromyalgia navigate their way through a contested illness experience, the conditions and challenges that arise in the particular context of SA have been examined and highlighted in this thesis.

The study explored the fact that narratives emerge with particular timings and spaces for discussion. All participants had a degree of distance from the apex of their symptom experience, and could reflect on their condition as a result. As demonstrated through the rich findings, by establishing solid and nurturing rapport with participants, most felt comfortable talking about their experiences. This was a critical component of the innovative research undertaken here, as accessing a personal telling of difficult experiences can be challenging for researchers and participants alike. By exercising reflexivity and sensitivity, this research was able to gain entry into perspectives and narratives which had not been spoken about extensively before.

This study adds a body of knowledge that is currently unavailable in the context of SA, and in prioritising the perspective of the patient, the gap between what is recommended and what is enacted has been bridged by this research. This research makes an important contribution towards understanding how people living with chronic illness, pain, and fibromyalgia relate to their condition

The findings were able to confirm that fibromyalgia is indeed a condition marked by complexity and multiplicity. In unpacking the illness experience of those living with the condition, it was possible to see the effects of credibility, legitimacy, scepticism, social constructions of health and illness and boundaries of 'normality' on the way people negotiate their chronic condition. A discussion on the roles of institutions, support structures, practitioners, and health systems that are drawn on in this illness experience, as well as the challenges faced in diagnosis, prognosis, and treatment options takes a prominent place in this thesis. The difficulties associated with forming responses to an insecure 'sick role' were also revealed through this research.

In drawing out the narratives of people living with fibromyalgia, it was shown that some were reticent to share their perspectives, as their story of encountering illness, and fibromyalgia in particular, was a difficult one to relate. Others felt that through their participation in this study, they were being given an opportunity to illuminate and connect with a body of common experience, which could be taken forward as an avenue of advocacy for fibromyalgia recognition in SA.

Overall, the innovative findings presented here demonstrated that consistent with the 'contested', 'amorphous' image of fibromyalgia, many of the participants continually questioned whether their diagnosis of fibromyalgia was legitimate. This was a reflection of the queries they faced from healthcare providers, explicitly from practitioners, and implicitly from medical aid schemes who supplemented the cost of the treatment, as well as from family members, friends, employers and colleagues at work.

The depth and richness of the findings attest to the study's success in accessing narratives of people living with contested conditions in the unique SA context of complex and unequal healthcare service. The study therefore makes an important contribution to knowledge of how people live with fibromyalgia. This was achieved through investigations of the processes involved in diagnosing fibromyalgia, and the interactions that people with the condition have with practitioners, as well as their utilisation of healthcare services in this context. Additionally, the responses that were developed by people with fibromyalgia to live and cope with the condition were critically discussed in this thesis. Many of the findings have applicable implications for the recognition and treatment of fibromyalgia in SA, and could be utilised as an innovative tool in furthering knowledge of the condition in this environment, through informing patients, practitioners, institutions, and workplaces, as well as peers and relatives of those living with fibromyalgia.

Fibromyalgia in SA is a relatively recently recognised phenomenon, and absorbing the experiences of those living with the condition became a useful means of contributing to

widening the range of knowledge that exists in this context. The study deliberately aimed to capture perspectives of patients with fibromyalgia, rather than taking a clinical stance on the subject. By providing qualitative understandings and an experiential analysis of these processes, an alternate perspective, which contrasted to the biomedical views of fibromyalgia, was produced. This offered insights into how people with the condition experience symptoms, respond to them, who they draw on, and what knowledge is influential in shaping their perceptions and actions.

Furthermore, and pertinently for the SA context, the impact of institutions, healthcare systems, practitioner knowledge and accessibility could all be seen through this study. This was because the patient was the lens through which these processes were viewed and by including their perspective, it was possible to capture how they adapt to and accommodate fibromyalgia as a part of their illness career and respond to the condition's demands in the bodily, identity and structural constraints that surround the illness.

The design of this study served the purpose of gaining perspectives from sources that are traditionally obscured from research agendas. In privileging the experiences of people with fibromyalgia over other narratives, this study illuminated the complexity and challenge of living with contestation and uncertainty. The replicable nature of this study's design means that processes relating to health and illness experience can be readily explored. In capturing complexity and multiplicity through the perspectives of those living with the chronic, contested condition of fibromyalgia, the research undertaken here showed the utility of narratives as an assistive and instrumental tool for gaining greater awareness and nuanced understandings of these experiences. Narrative inquiry is therefore recommended for studies that are interested in gaining insight into health and illness experiences, particularly those that are characterised by contestation, complexity, flexibility and reflexivity, like fibromyalgia.

This study showed how some people with fibromyalgia dispensed with the label entirely, or stated that it was a minor component in their health schema. The shift in use of the label of fibromyalgia generally occurred when the person had mostly recovered from their symptoms, and they were managing their condition through medication and were drawing on a "quest"

narrative when speaking about their illness experiences (Frank, 1997). Displaying this complexity, the structural interactions between the patients and various social institutions and actors, and the agency exercised by participants, when their symptoms had subsided, their condition was rendered manageable, and a new sense of 'normality' had developed, were central achievements of this study.

In taking fibromyalgia out of the foreground and relocating it to the background in their illness career, the people who were able to achieve this could be seen to be coping with the condition. As they had resolved much of the uncertainty, insecurity and confusion that defined many of the earlier stages of their sickness, they had figured out strategies for success and what works which was a theme explored in-depth in this study. Future research could attempt to systematise the responses formulated by people with fibromyalgia in the course of their illness career. The recommendations could be used in developing medical guidelines for addressing fibromyalgia. This would be helpful since there is little known about fibromyalgia in SA, and the information that is available is distributed unevenly.

The narratives of people living with chronic conditions are a useful means for understanding the contestation, legitimation, scepticism, stigma and disregard that circulate this illness experience. By exploring the understandings of diagnosis, sickness, prognosis and illness identity held by people with fibromyalgia, it was also possible to see the treatments utilised, healthcare services and practitioners who they interacted with, as well as the different forms and roles of social support which were available in the course of their illness career. This lent support to the argument that prognosis is critical for legitimacy and credibility in illness experience, in moving the person to patient and allowing forthcoming access for that individual to the 'sick role', associated practitioners and treatments. With chronic pain, there is variability in the frequency of pain and the severity of it, which makes it harder to predict, sufficiently capture and explain what is happening, when symptoms might occur and what can be done to overcome them (Richardson, 2005).

In the course of the interviews, many of the participants spoke about being "sick" which, for them, was different from fibromyalgia as the latter was an embedded, underlying component

of their illness and health experience. Existing in the liminal space of living with constant pain and frequent exhaustion meant that the boundaries between being well and ill were difficult to view clearly (Jackson, 2005). This is delineation from the view that recognition and legitimacy are the same. While recognition often translates into legitimacy with most diseases, fibromyalgia confounds this process (Stockl. 2007, Barker, 2011). By investigating people's illness experiences and their interactions with medical and political institutions and actors in this process, the relations of power and discourse moving through the experience were effectively captured. This is important in understanding the scene in which people living with fibromyalgia are negotiating their illness, and the role that medicine plays in allowing their experiences to be validated and dealt with effectively. Additionally, it was possible to see how this translates into their social ability to operate functionally within society.

The challenges faced in gaining institutional and social support for the experience of fibromyalgia were analysed extensively. It was found that, due to the insecurity and contestation that surrounds the condition, people with fibromyalgia have to often be assertive, insistent, and careful about embodying their illness identity. Therefore, this research was able to illuminate the experience of fibromyalgia in a holistic manner, and accounted not just for the personal experience, but also those structural interactions that shape the process of living with a chronic condition. In contextualising personal narrative in broader society, and using in-depth descriptions with expert opinion and media content analysis, a wider range of perspective was captured, in order to analyse the findings and bolster the arguments made herein.

An important finding that emerged from this study was the continuous need felt by participants to articulate clearly and insistently to those they interacted with in the course of their social lives, that their experience was severe and chronic. In uncovering these experiences, there was an evident sense that they deserved understanding and accommodation in that context, similar to people suffering from other 'legitimate' conditions. As highlighted by the narratives collected for this study, the frequent disparaging disbelief that the participants encountered occasionally diminished their ability to embody the illness identity of fibromyalgia. This made them cautious about sharing the diagnosis for fear of enacted stigma in the form of social rejection.

The fact that the diagnosis of fibromyalgia functions in a 'partial' manner, in giving a label but not an explanation or effective treatment, and only conditional entry into the 'sick role', was another key finding of this research. Acknowledging that the process happens, and confirms what is known about contested conditions and the experience thereof, was only half the task of this research. Untangling exactly how people adapt to fibromyalgia in the context of uncertainty, delegitimation, scepticism and disregard, and carve out strategies for successfully coping, overcoming and living with the condition was the purpose of this research. The research presented here was able to show the responsiveness of people with fibromyalgia in confronting their symptoms, and the patterns, relations, and reactions of the structures, institutions, practitioners and people that constitute this illness experience were explored.

The debates that feature in the literature around legitimacy and contested conditions were extensively covered in this thesis. It was shown through this research that the process of diagnosis is both a site of compromise and contestation, and when biomedicine is unable to account for patient experience, dissatisfaction can emerge (Brown, 2011). This research discovered that during this time, a patient might consult with a range of health care practitioners, always searching for a better, and more legitimate, explanation to give their experience medical and social meaning and validate them as a ‘sick’ person. These processes were highlighted through the narratives collected in the course of this study. Future research could aim to systematically catalogue the diagnostic process and treatment recommendations that are currently available in SA. The findings in this thesis are original and make a novel contribution in commenting on illness experience in SA from an exploratory, narrative perspective (Keikelame and Swartz, 2013).

Within the interviews conducted with the participants, there was much discussion of the effects of the uncertainty surrounding fibromyalgia as a diagnosis. The notion that bodies are controlled and have forces of power exercised on them was clearly shown in the narratives of my participants, as the legitimacy of their experiences was subject to the wills and beliefs of their practitioners, employers, and family. They needed to persuade them that what they were

going through in experiencing the symptoms of fibromyalgia was sufficiently overwhelming and present, despite appearances. The limited knowledge that surrounds chronic pain experience contributes to the misconceptions of conditions that have the symptom as a feature, like fibromyalgia. By focussing on chronic pain experience, and giving preference to the subjective telling of the ways of living with the condition, this research was able to expose processes, interactions, memories, stories, responses, practices, and perspectives that are generally hidden from view. Expanding the discourse of pain experience was therefore a useful, innovative contribution of the research undertaken here.

Expanding the view of prognosis as a site for understanding, explaining, and absorbing the condition of fibromyalgia was a worthwhile exercise, which was displayed extensively in the narratives related by people involved in this study. For them, the emphasis was less on understanding the specific causes of the condition, but more on the urgent need to find relief from symptoms, and interpret the patterns of the illness, so they could respond efficiently and effectively to fibromyalgia in their lives. This was a process fraught with complications, but it does reflect Christakis's (1997) explanation that, in conditions that prove to adhere atypically to the typology of diagnosis and assumed prognosis with effective treatment options, there is a greater attention given to understanding the trajectories and prognoses that can be offered in order to encapsulate and address the experience of these illnesses. In bringing attention back to a condition that atypically adheres to the traditional 'sick role' and prognostic process, this research performed an important role in providing a more nuanced understanding of the lived experience of coming to terms with an illness that is marked by uncertainty.

The study undertaken here was able to gain insight into complex, often hidden processes, and provided a valuable analytic framework for interpreting the diagnosis, prognosis, treatment, social support and institutional interactions that characterise the illness experience of fibromyalgia. An innovative contribution of this thesis is its ability to identify and shift the site of contestation from diagnosis to prognosis. This was shown by the fact that difficulties faced in attaining diagnosis were compounded by an uncertain and malleable prognosis, which in turn presented challenges to those attempting to respond to fibromyalgia in this context. This is an original perspective of established debates and discussions within the field

of chronic conditions and contested illnesses, as the conflicts and tensions surrounding diagnosis were also analysed in terms of prognosis in this study.

Where the orientating points of expectation and response are lost, because the prognosis and treatment recommendations are unclear with fibromyalgia, the ways that people navigate through the experience was an important perspective to analyse. In utilising patient narrative, this research highlights the processes and practices drawn on by people with fibromyalgia, and provides insight that could be helpful in developing practitioner and treatment recommendations for fibromyalgia in SA. Capturing the complexity and multiplicity of fibromyalgia is challenging in any field, but the research discussed here made deep inroads into understanding the totality of the experience, and was able to show where experience deviated from expectation and how responses were formed.

Therefore, using people living with a condition as a lens for understanding these broader processes was a productive means of developing a clearer picture of fibromyalgia as an illness experience. Nevertheless, further research could explore, more deeply, the relocation of contestation to the site of prognosis, rather than diagnosis. This could be useful in revealing the continuation of delegitimation after the point of receiving a label. It could also highlight the responses developed to overcome the contestation, and explain the roles of various actors and institutions, such as medical practitioners and healthcare structures, in the process. The research undertaken here showed a need for concrete responses and recommendations in addressing fibromyalgia, which would be assistive in providing organization and support for those with condition while navigating through this chaotic illness experience.

While there are studies elsewhere that discuss treatment adherence in relation to fibromyalgia, this study has gone further in discovering and exploring the motivations, barriers, facilitators, and interactions that determine how people with the condition access treatment, and are able to continue managing their condition. This study was able to show that the disparate distribution of knowledge surrounding fibromyalgia in SA, as well as the inability to access specialists required to make the diagnosis and access treatment, creates

obstacles for people with the condition when attempting to respond to their symptoms.

Furthermore, in terms of chronic illness management, there are active limitations imposed by the structure of healthcare in SA. The instrumental role of medical aids in effecting treatment access and adherence in this context is interrogated as an example of these limitations. Noting the changes in help-seeking behaviour of people with a chronic condition, like fibromyalgia, and the effects of medical aid access and coverage on the way this process plays out in SA, were critical findings of this research. These issues emerged spontaneously in the course of the study, and were pertinent in the discussions detailed in this thesis. As it was beyond the scope of this study, areas of further research could investigate the role of medical insurance in shaping treatment access and outcomes more deeply, as well as the particular strategies used by those with chronic contested conditions like fibromyalgia.

The research described in this thesis aimed to mitigate this deficiency by explaining the cumulative effect of chronic illness on social life. In the spaces created by insufficient medical care and medical aid supplementation for treatment costs, families provide practical and emotional support for people living with fibromyalgia. In the study discussed in this thesis, the financial and personal care afforded to people with the condition through their families was an important finding to emerge from the research process. In looking at the experience of fibromyalgia from the perspective of someone living with the condition, this study uncovered how "balance" is critical to managing the fluctuating disappearance and reappearance of symptoms. It also showed that there is loss of legitimacy found in the insecure prognosis of the condition. The role of social support in shaping the experience of fibromyalgia has been displayed throughout this study.

Understanding the recommendations for flexibility, adaptation, acceptance, and reflexivity on the part of patients and those they work with in managing fibromyalgia, was another important finding of this research. Through this, an explanation of why this process is particularly challenging in the face of immovable social structures and interactions is offered. Frank (1997: 6) states that “the postmodern experience of illness begins when ill people recognize that more is involved in their experiences that the medical story can tell. The loss

of a life's map and destination are not medical symptoms". Importantly, this indicates the flexibility required in addressing fibromyalgia.

This was particularly highlighted through this study, as the narratives showed that a component of successfully living with fibromyalgia involved reflexivity on the part of the patient, and responsiveness from the institutions, practitioners, and people who could offer support. Flexibility is required in three ways; in conceptualising what the symptoms as a collection mean; in responding to them effectively; and finally in predicting the trajectory of condition - a point that was demonstrated continuously throughout this thesis. Further research could explore the central role of flexibility in explaining responses to fibromyalgia and other chronic conditions. The interactions between a patient that requires reflexivity, and an institution that is defined by organisation, categorisation, and predictability, like biomedicine, were displayed in this thesis, and could be explored more deeply in future research.

From evidence gathered in the course of this study, it was apparent that the attitude of the patient towards their illness certainly contributed to different outcomes. This was particularly seen with regards to coping with the experience. Those people who were able to view their symptoms as manageable rather than overwhelming fared better than those who could not see beyond the immediate circumstance of their pain and exhaustion. There were additional factors that shaped this picture, such as symptom severity, practitioner cooperation, familial and social support as well as workplace and domestic life accommodation. Gaining a better understanding of how treatment plays out for people living with fibromyalgia in SA was useful as it gave insight into the strategies used, the successes found and constraints encountered.

Becker et al (2004) assert that there is consensus about the important role self-care plays in the management of chronic illness, but there is relatively little known about how individuals enact these strategies as every day practices. In presenting narratives and experiences of chronically ill individuals living with fibromyalgia, this study aimed to contribute knowledge about the meanings, behaviours, strategies and outcomes of addressing this illness experience in the SA context. The purpose of the study undertaken here was not to offer a generalisable

account of fibromyalgia. Rather, the aim was to gain more nuanced understandings of the experience through the narratives of a select group living with the condition. Linking these experiences to the context of SA goes further than many other studies based in this environment, and therefore makes a significant contribution to widening knowledge on fibromyalgia through the perspective of the patient.

An important issue to emerge from the research detailed in this thesis is that of adequate financial support from medical aid schemes for consultations, treatments and medicines for those living with fibromyalgia. The adaptive strategies that people with the condition utilise to continue their treatments, and cope and live with a chronic illness, was an additional component of the analysis in this thesis. Related to this was the role of pro-bono treatment offered by the health care practitioners, and the social capital drawn on in manoeuvring around and through the restrictive medical aid schemes was discussed. The continual negotiation of self and sickness through the access of treatments, and ability to cope with the condition, was a prominent theme that emerged in the narratives collected through this research. Unfortunately, the overwhelming trend of experience related in the narratives of this research shows that medical aids are actively obstructive in the attempts to manage fibromyalgia as a chronic condition. There is little known about how medical aids interact with and respond to chronic conditions like fibromyalgia, and this area would benefit from further research.

Through the study described within this thesis, it was found that institutional responses in terms of workplace accommodation and sickness attendance for those living with fibromyalgia was varied, and there was little regulation evident. In interacting with employers around their chronic condition, those involved in the study described their fear of diagnosis disclosure and the importance of their continued need to work, both financially and personally. Where workplaces were able to display adjustment latitude, it also appeared that the employee concerned was able to draw on their status in the workplace and social capital and networks to ensure their condition and workload could be negotiated around in allowing them to stay employed there. In cases where flexibility and adjustment latitude were not available, the person with the chronic condition left their job and moved into an industry or position or contract that allowed them to work around the flare-up of symptoms more easily

By bridging the fractures between patient experience and medical perspective, this thesis makes a valuable contribution in learning how people with chronic pain conditions, like fibromyalgia, are able to navigate through an often challenging illness experience. More specifically, the study investigated the ways in which people living with medically ill-defined conditions are able to make sense of their health status and treatment options available in the SA context. The ways in which a patient draws on government, biomedicine, institutions, family and social networks to navigate their way through this contested and confusing illness experience was explored.

The sources of support drawn on by people with fibromyalgia, and the knowledge shared in these interactions were central themes in this thesis. This was done by identifying and focussing on the barriers and facilitators they encounter, and the institutional and environmental structures that shape the outcomes of this process. It was shown that challenges of legitimacy, credibility, access, support, recognition, contestation, and stigma continue to consume the experience of fibromyalgia. This occurs at all junctures in the illness career of someone with the condition, from pre-diagnosis, to diagnosis, when formulating prognosis and treatment options, and learning to live with fibromyalgia as a part of ordinary life.

Family, in particular, impacts on the manner in which people living with fibromyalgia are able to accept the condition, adapt to it, and adhere to treatment recommendations, in both positive and negative ways. For many of the participants of my study, having access to medical aid was rarely an individual undertaking which means that family was always involved. The individual with fibromyalgia was either accessing medical insurance through their family, or they were providing access to others through their medical aid. Importantly for this study, there are also inconsistencies seen in the extent and type of medical coverage offered through medical insurance for people with fibromyalgia and their families. This in turn affected their healthcare utilisation.

Additionally, workplaces and peer groups are important areas of support, which provide care, information, and accommodation to the person with fibromyalgia. Practitioners were another strand of support that was shown to be instrumental in dispensing a label and providing

effective medications and treatments. Practitioners are also important in validating the experience of fibromyalgia, and enabling the patient to absorb the condition into their lives and realise the chronicity of the condition. These interactions and sources of support were discussed extensively in this thesis. This shows the critical role of an articulate (and occasionally insistent) patient, a recognising practitioner, an accessible healthcare system, and a supportive social network belonging to the patient in living with fibromyalgia in the context of SA.

The research also explained the sources of knowledge drawn on by people living with fibromyalgia in SA, and it was seen that there was a preference for internet-based information that had a strong presence of biomedicine in the content and tone. Internet-based explanations of fibromyalgia are readily available and easier to access than information from medical practitioners. It was evident that many participants within this study consulted the internet to find meanings and explanations of their symptoms, before and after their diagnosis. Additionally, they frequently searched for treatments on the internet, and in the course of their browsing; they also encountered support groups, which many of them found unhelpful.

The predominant types of information that were discussed in interviews related to the features of fibromyalgia and the uncertainty that surrounds its aetiology; possible routes of treatments and medications that were available; practitioner contact details; and internet-based support groups and personal blogs that detailed the experience of others living with the condition. The media content analysis conducted in this study confirms evidence of information that falls into those categories. In the narratives collected in this study, there was discussion of the internet as a source of health-related knowledge. While participants utilised internet-based information to make sense of their condition and the demands of the experience, they were less taken with the personal stories and support groups they found online. This was explained through the characterisation of those e-spaces as having a "whiney", catastrophising tone that participants in this study found to be unhelpful in their attempts to manage and overcome the condition. It was important to understand both what information was being accessed and how it was being utilised, and given the omnipresence of online support groups and blogs related to fibromyalgia experience, it is interesting that my participants were reluctant to engage with that platform.

As these networks are sources of convincing knowledge (if not always empirically reliable), then their appeal is obvious as demonstrated by Bury (2000). The congruity between people's systems of health knowledge and their social perceptions, beliefs, norms and values all lead to lay beliefs around health issues impacting on the authority and dominance of biomedical knowledge within society. For people living with fibromyalgia in SA, this knowledge and the sources from which it was drawn continually shaped their experience of the condition. Furthermore, the sources and sites of knowledge were an integral part of the process of absorbing, reinforcing, contradicting and interpreting the information and advice offered by biomedicine and its practitioners in the course of their illness career. These surrounding sources and the knowledge they provided were an important space of making the experience of a contested and medically and socially invisible condition 'real' and legitimate. Explaining the types and content of information drawn on by people with fibromyalgia, and other chronic conditions, in the course of their illness careers would be an area that would benefit from further research.

In giving a unique perspective of the experience of a complex condition like fibromyalgia in the specific context of SA, the research explored in this thesis was groundbreaking and offers fresh perspectives on an emerging phenomenon. Furthermore, by utilising the narratives of those living with the condition there is opportunity to understand how people experience diagnosis, prognosis, treatment, management and interactions that are inherently complicated by the contested and confusing nature of fibromyalgia. The research undertaken was able to explain what knowledge is received, and how it is used in the continual process of clarifying the meanings, experiences and outcomes of living with fibromyalgia.

The research undertaken here explored fibromyalgia as an illness experience, and was able to draw attention to the complexity and multiplicity involved in living with the condition. The challenges and contestation that characterises this illness experience made for rich findings. In displaying the mechanisms, processes, people and institutions that shape the capacity of those living with the condition, this research was able to provide an analysis of these experiences that was holistic and critical in approach. By investigating these experiences in

the context of SA, the picture of chronic illness and contested conditions in this environment was more clearly displayed, and the ways that people with fibromyalgia access healthcare, treatments, knowledge, and support for the condition was explained.

The research simultaneously slotted into a growing body of knowledge centred on chronic illness experience, and furthered the available explanations of how people enact health behaviours and manage conditions like fibromyalgia in the particular context of SA. The research is not generalisable, as it was designed as a case study, however the findings are unique for the SA context, and the access gained to feelings, perceptions and experiences of living with fibromyalgia in this environment is unique. The research provides an alternative perspective to what is known about how people live with fibromyalgia in SA, and this was achieved by giving insight to the experience through the narratives of those with the condition. While it was beyond the scope of this study, it is important for the institutional responses to chronic illness to be explored more deeply in SA. As lifestyle and chronic conditions become increasingly prevalent in this context, knowing how they play out and how to respond is a useful undertaking.

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APPENDIX 1: Participant Information Sheet

Re: Participation in PhD Research Project **August 2012**

Following our initial discussion, I would like to invite you to participate in a research study investigating *the illness experience of fibromyalgia in South Africa.* I am a PhD student, enrolled in the Health Sociology Programme at Wits.

There is little known about fibromyalgia in South Africa specifically in relation to the personal experience of diagnosis, prognosis and treatment. Capturing the stories and narratives of people living with fibromyalgia is a central concern of the study.

I view you as a research partner and not simply as a participant, as your insight and opinions form an integral part of the outcome and findings of this research project. Your participation in this study is voluntary and there is no reward for participating or penalty for not participating. However, by participating in this project I believe you will have the opportunity to reflectively learn about your experiences and story of fibromyalgia. I also feel that your involvement will contribute to the strengthening of advocacy for the recognition and acceptance of fibromyalgia in South African society. Involvement in this study requires your participation in:

- A series of 2 to 3 repeat interviews.
- "Diary" entries detailing your reflections, thoughts, opinions and stories between the interviews.

You will not be obliged to answer any questions with which you are uncomfortable and can decline to respond to any questions asked. You may terminate your participation in the research project at any stage.
All data collected through the research process will be treated with the strictest confidentiality and you will remain anonymous. A copy of the final report will be provided. The results of the research will be submitted as part of the requirement for my Health Sociology PhD thesis. If you have any concerns regarding the study or if you require any additional information, please contact me or my supervisor, Prof Leah Gilbert.

Kind regards,

Silvie Cooper
076 600 5001 or silvco@gmail.com

Prof Gilbert
leah.gilbert@wits.ac.za

APPENDIX 2: Participant Consent Form

I hereby confirm that:

I, _____ have been briefed on the research that Silvie Cooper is conducting on *"The experience of medically ill-defined conditions: a narrative study of fibromyalgia in South Africa".*

I understand what participation in this research project means.

I understand that my participation is voluntary.

I understand that I have the right not to participate in any process that I do not feel comfortable with.

I understand that I have the right to withdraw my participation in the research at any time I so choose.

I understand that any information I share will be held in the strictest confidence by the researchers.

Please tick the following:

I hereby request that I be guaranteed anonymity ☐

I hereby consent for the interview to be recorded. ☐

I hereby request a copy of the research report ☐

Signed by_____ on____/____/201__ at_____ (place)

Signature: _____

APPENDIX 3: Diary template

Please use this diary in the same way you would a journal.

Record any instances of pain, discomfort, experience related to your condition.

Please record any memories, thoughts, opinions, feelings that would add to your explanation of your illness experience discussed during our interview.

- What do you know about fibromyalgia as a condition?
- Do you remember what life was like before you started experiencing the symptoms of fibromyalgia?
- How has your life changed since discovering you had the condition?
- How do you feel about your diagnosis? Does it make sense to you?
- How do you feel about your prognosis? What have you been told about how to live with the condition? Are you able to adapt your life around the condition and prognosis?
- How do you feel about the treatment offered? Is it sufficient? What effect does it have? Does it improve or hinder your health status?

Who do you speak to about your illness experience? Family? Friends? Health-care practitioners? Conventional (Medical/Specialist) or Complementary and/or Alternative Practitioners?

- Do you feel supported in your illness experience?
- Do you ever have to convince people that fibromyalgia is a real medical condition?
- Do you interact with support groups or forums? Either in a physical space or online?
- Do you find them helpful? Do they provide useful information? Please explain your answer.

APPENDIX 4: Interview Protocol

- How do you understand the concept of health?
    a. Are there particular activities involved in attaining or maintaining health?
- How do you understand the concept of illness?
    a. What does it mean to you to be ill?
    b. Are there particular activities involved in recognising, addressing and dealing with illness?
- Do any of the beliefs or perceptions mentioned correlate with a particular social/cultural/religious identity?
    a. How do you describe yourself?
        i. Describe social/cultural/religious background (Probe Question)
        ii. Particular beliefs attached to that social identity (Probe Question)
        iii. Practices that are undertaken as part of identity (Probe Question)
- What sources of health "knowledges" do you encounter in your social environment? Where do you learn about health and illness from?
    a. What information emerges from these sources?
        i. List sources and then list type and content of information each source provides.
    b. How do you determine the credibility of the source?
        i. What makes you believe that what is being told to you is true/valid?
        ii. How do you make sense of each source and the information it provides? What about the source and what is being said "speaks" to you in relation to health and illness?
        iii. Which sources are viewed as "credible" by you?
- A theme found in the literature explains that often, getting a diagnosis of fibromyalgia is "difficult" and "elusive". How did you achieve a diagnosis of fibromyalgia?
    a. How did you recognise that you were ill?
        i. What symptoms did you experience?
        ii. How did you know "something was wrong or out of balance"?
        iii. Who did you consult with in order to gain the diagnosis of fibromyalgia?
            1. Biomedical practitioners? Alternative practitioners? Friends? Family? Colleagues? Lay knowledge referral networks? (Probe questions)
    b. What steps did you take in terms of getting better? (Illness behaviour)
    c. What has so far confirmed to you that your experience is real? That the experience doesn't just exist in your head and is medically and socially legitimate?
    d. If treatment was offered, what was it and to what extent has it helped or hindered your health status?
- Did you, as the patient, consult with other Complementary and Alternative Medicine (CAM) practitioners as well as BM practitioners?
    a. What was information, explanations and treatments offered by the CAM practitioners?
    b. Did this hold validity for you? Why or why not?
- How do you identify yourself?
    a. Has this definition of self changed in your illness career?
    b. What is the perceived effect of your family and community in explaining, helping or hindering your condition?

APPENDIX 5: Participant Demographics

Name	Age	Occupation	Years since Diagnosis	Marital Status	Area of Residence
Chloe	23	Freelance Writer	5	Single	Johannesburg
Jenna	27	Freelance Writer	Self-diagnosed	Single	Durban
Claire	37	Psychologist	2	Divorced	Johannesburg
Teresa	25	Student	7	Single	Pietermaritzburg
Alison	23	Student	3	Single	Johannesburg
Zainab	51	Administration Manager	20	Divorced	Johannesburg
Kate	31	Swimming Instructor	10	Married	Johannesburg
Rebecca	32	Swimming Instructor	4	Single	Johannesburg
Frances	59	Veterinary Nurse	18	Married	Pietermaritzburg
Shreela	48	University Lecturer	9	Divorced	Johannesburg
Beth	57	Programme Manager	Self-diagnosed	Married	Johannesburg
Connie	39	Human Resources Director	10	Married	Johannesburg
Michelle	51	Programme Manager	7	Married	Johannesburg
Karen	24	University Lecturer	2	Single	Pretoria
Helena	49	Consultant	6	Single	Johannesburg