

# FACTORS AFFECTING MEDICATION ADHERENCE IN RHEUMATOID ARTHRITIS

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of Master of Science in Medicine

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## DECLARATION

I, Boitshoko Oageng Kobue, declare that **“FACTORS AFFECTING MEDICATION ADHERENCE IN RHEUMATOID ARTHRITIS”** is my own work. It is being submitted for the degree of Master of Science in Medicine in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

**Boitshoko Oageng Kobue**

.....

The ..... day of ....., 2013

## DEDICATION

This dissertation is dedicated to my parents, Monnana and Mumsy Kobue, who have always supported my dreams and quest for higher education. I would not have come this far had it not been for your inspiring words and unwavering faith in my abilities. I will remain eternally grateful for your encouragement during the times I felt like giving up. I hope I have made you proud.

## PRESENTATIONS ARISING FROM THIS DISSERTATION

### Poster Presentations

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## ABSTRACT

### **Factors Affecting Medication Adherence in Rheumatoid Arthritis**

**Introduction:** Rheumatoid arthritis (RA) is a chronic inflammatory disease that typically affects the wrists and small joints of the hands and feet. Its progressive nature can result in severe deformities and the inability to perform daily tasks. RA requires lifelong medication to ameliorate symptoms of the disease. The lifestyle changes necessary to achieve continuing functionality include taking medication daily. This is an area that has not been adequately researched.

**Aim:** To qualitatively determine the factors affecting RA patients' adherence to chronic prescribed medication.

**Methods:** A semi-structured interview schedule was used to interview 18 patients from an out-patient Rheumatology Clinic at a Johannesburg hospital. The patients were purposively selected and invited to participate in the study. The individual interviews were conducted in the home language of the participant and video-recorded. Interviews were then translated into English and transcribed. The patient accounts of their medication taking habits were compared to their hospital records regarding prescribed medication. Thematic Analysis was used to identify the prominent issues raised in each interview. These categories were then grouped into themes that occurred across the data set. Interviews with two members of staff and ethnographic observations were also conducted to get a better understanding of how the clinic functions.

**Findings:** Four main themes were identified. Firstly, the effect of RA on the living experiences of patients. This dealt with the manner in which RA affected their quality of life and how those experiences affected adherence. Secondly, interactions with medication, which explored the manner in which patients used both prescribed and non-prescribed medication. Thirdly, patients' experience of healthcare services. This explored the functioning of health systems and how patient adherence

can be subsequently affected. Lastly, level of understanding and access to information which explored the effect of the knowledge deficit that exists in patients regarding biomedical concepts and how that contributes to their adherence levels.

**Discussion:** The findings showed that more can still be done by healthcare professionals to improve patients' experience of the healthcare system, and to promote patient adherence to medication. The factors that affect adherence provide many avenues for further research, areas in which interventions can be implemented to improve the quality of healthcare being provided to South African communities.

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## **LIST OF ABBREVIATIONS**

ACR	American College of Rheumatology
AIDS	Acquired Immune Deficiency Syndrome
Anti CCP	Anticyclic Citrullinated Peptide
CNS	Central Nervous System
COX	Cyclooxygenase
CRP	C-reactive Protein
DMARDs	Disease Modifying Anti-Rheumatic Drugs
DNA	Deoxyribonucleic Acid
ESR	Erythrocyte Sedimentation Rate
EULAR	European League Against Rheumatism
FDA	Food and Drug Administration
GIT	Gastrointestinal Tract
HIV	Human Immunodeficiency Virus
INCB	International Narcotics Control Board
INR	International Normalised Ratio
IV	Intravenous
MCC	Medicines Control Council
MTX	Methotrexate
NSAIDs	Non-Steroids Anti-Inflammatory Drugs
OTC	Over The Counter
RA	Rheumatoid Arthritis

RF	Rheumatoid Factor
SC	Subcutaneous
SLE	Systemic Lupus Erythmatosus
TB	Tuberculosis
TNF $\alpha$	Tumour Necrosis Factor $\alpha$
WHO	World Health Organization

## CHAPTER ONE: INTRODUCTION

As a young pharmacy graduate, my education has directed my attention towards understanding the functioning of medicines and how they are used. I have been taught about the role of the pharmacist in the maintenance of community health through the principles of pharmaceutical care.

As I moved into the working environment, I realised that a lot of what I had been taught to expect and been prepared for was not happening. The principles of pharmaceutical care were not always in practice. This led me to ask questions about why reality was so different from theory.

I could recognise that the working conditions for pharmacists, and other health workers, often did not inspire them to perform at their best. The ratio of pharmacist to patients was such that the pharmacists were overworked and did not have enough time to counsel each patient as they should have. Medicine was often out of stock which made dispensing difficult and reduced morale. More importantly, these issues compromised the pharmacist-patient relationship and the service provided to patients. I also considered the effect that this sub-standard service would have on the well-being of patients. This thought process was the motivation for this study.

In health practice, the main goal is to improve the health related quality of life of the patient and community and to promote good health. As a pharmacist in clinical practice, it is my responsibility to ensure the safe and efficacious use of medicines, and to educate and counsel patients about their respective drug therapies (Pharmacy Act 53 of 1974; Ibrahim, 2012; Ramanath *et al*, 2012). This is exceptionally important for patients on chronic medication who have to rely on drug therapy to

maintain good health for the rest of their lives. Rheumatoid Arthritis (RA) is one such condition where patients need to take daily medication to relieve their pain and reduce chances of physical disability. The incorporation of daily medication into their lives can be a difficult transition for patients, particularly in the South African context where issues such as low literacy levels, and cultural and language barriers can make it hard for patients to understand the necessity of such medication (Penn *et al*, 2011). The pharmacist can play a critical role here by counselling patients about their medication and how it ought to be used, and by explaining biomedical concepts in a manner that will be easily understood by patients (Ibrahim, 2012; Ramanath *et al*, 2012). Such communication has been proven to be essential in the achievement of adherence to medication in RA (Salt *et al*, 2012).

RA is a condition which affects up to 1% of the world's population and most of those affected are female (Clements, 2012; Hodkinson *et al*, 2011, Symmons *et al*, 2000). It thus presents less of a burden on the health system when compared to diseases such as HIV/AIDS, tuberculosis (TB) and Hypertension which are more prevalent in South Africa (Cramm *et al*, 2010; Ncama *et al*, 2008). As a result, little information exists on RA medication adherence in this country.

The literature revealed many studies that looked at the effect of disease, RA included, as well as the various drugs used. However, not enough of these studies include the patient perspective and experience of health care. Thus, this study focuses on patient experiences and perceptions regarding RA and adherence to the treatment. This study represents my attempt to "walk in their shoes" and begin to understand patients' experiences of healthcare, medication and adherence.



## **OUTLINE OF THE RESEARCH**

### **Chapter One**

This chapter has provided my own personal experience of the pharmacy profession and how I found that it differed from the theory I had been taught while still at university. It briefly describes how I identified the problems related to pharmacy practice and how they could potentially affect the adherence levels of patients diagnosed with chronic conditions and RA specifically. I also make mention of some of the literature available on both adherence and disease progression. This chapter also identifies that there is a shortage of literature that focuses on the patient experience, which provides the premise for this study.

### **Chapter Two**

This chapter is divided into six sections, namely rheumatoid arthritis; treatment for rheumatoid arthritis; conventional medicines used in the treatment of rheumatoid arthritis; complementary medicines used in the treatment of rheumatoid arthritis; non-medicinal treatment for rheumatoid arthritis; and the legal aspects of medication.

The first section provides an overview of RA as a disease. It describes the symptoms with which the disease presents and the methods used to diagnose it. Classification of disease severity is also described.

The next three sections focus on how RA is treated. Literature is used to describe the conventional, complementary and non-medicinal measures used to alleviate the symptoms of RA. The positive and negative aspects of each treatment method are also highlighted.

The last section details the legal framework that governs the provision of pharmaceutical products in South Africa, in accordance with the Medicines and Related Substances Act 101 of 1965.

## **Chapter Three**

Chapter Three is divided in five sections, namely medication taking principles; the South African healthcare system; adherence in South Africa; measurement of adherence; and healthcare provider-patient communication.

The first section focuses on the trend in medical practice to advance medication-taking principles from compliance to adherence and eventually concordance. The principles are described and compared with one another.

The next two sections focus on South Africa specifically. The current state of the healthcare system is described and the pros and cons of the system are discussed. There is also a review of the existing adherence literature.

The last two sections focus on how adherence is currently measured and how the methods are generally quantitative in nature. The need for a more qualitative approach is highlighted. Communication between patients and healthcare providers is discussed as well.

This section identifies the need for a study such as this and provides an argument for why it is necessary to qualitatively analyse adherence and the patient experience in South Africa.

## **Chapter Four**

The methods chapter is divided into nine sections, namely aims and objectives; research design; research site; participants; pilot study; data collection; data analysis; rigour; and ethical considerations.

The first section describes what this study aims to achieve and the objectives it plans to fulfil.

The next four sections describe the manner in which the study was conducted, as well as the site where the study was conducted. It provides supporting literature for the methodologies chosen to conduct this study. The participant demographics are also described.

The data collection and analysis sections describe the methods implemented to bring about the findings of the study. These methods are justified using existing qualitative literature. The rigour section highlights the measures that were implemented to ensure that the findings of this study are truthful and objective.

Finally, the ethical considerations of this study are discussed, as well as the means implemented to ensure that the study was ethically sound.

## **Chapter Five**

This chapter is divided into four themes, namely effects of RA on living experiences; interactions with medication; level of understanding and access to information; and experience of healthcare services.

The first theme highlights the manner in which living with RA has impacted on the daily lives of the participants. The physical and emotional effects of the condition are described, as well as how these affect their adherence levels. The role of effective support systems in the achievement of adherence is highlighted.

The second theme reports the patients' interactions with conventional and complementary medication. This theme describes how patients access medication and the effect the medication has on their experience of RA. The issues of generic substitution and polytherapy are also discussed in relation to how they can affect patient adherence levels.

The third theme describes the patients' level of understanding about RA and its treatment. It describes the sources with which they consult for information regarding RA and their medication. The patients' interactions

with healthcare providers, technology and community members reviewed as well. The effect of all these interactions on the achievement of adherence is reported.

The last theme expresses the patients' experience of various sectors of the healthcare system and how these experiences affected both disease progression and adherence.

## **Chapter Six**

The discussion is divided into five sections, namely pain and disability; medication and medication taking; the need for information; implications; and limitations.

The first three sections provide a "bird's eye-view" of the findings presented. The findings are discussed in relation to the sections and the effect they have on adherence and disease progression.

The implications section discusses the effect this study can have on health practice and policy, theory and future research. The information provided by this study is placed against the existing literature so as to describe the benefit of conducting a study such as this.

The limitations section reviews the possible shortfalls of this study regarding the chosen methodologies.

## **Chapter Seven**

The final chapter concludes the study and sums up all the issues raised throughout this dissertation.

## CHAPTER TWO: BACKGROUND – RHEUMATOID ARTHRITIS AND ITS TREATMENT

### RHEUMATOID ARTHRITIS

Rheumatoid Arthritis is a “chronic, inflammatory disease associated with functional impairment and deterioration in patients’ health related quality of life” (Picchianti-Diamanti *et al*, 2010, p821). It is an auto-immune disease which means that the body’s immune system mounts an attack against its own healthy tissues in the joint, resulting in the characteristic pain and inflammation (Clements, 2012; Kaur *et al*, 2012). This disease is estimated to affect up to 1% of the global population, affecting twice as many women than men (Lee *et al*, 2012). In order for a patient to be diagnosed with RA, they need to present with at least four of the following seven symptoms in accordance with the criteria set by the American College of Rheumatology (ACR) in 1987 (Clements, 2012; Ncayiyana *et al*, 2003):

- Morning stiffness that persists for longer than an hour.
- Inflammation in at least three joints.
- Inflammation in the hand and wrist joints.
- Symmetrical arthritis.
- Rheumatoid nodules.
- Positive test for rheumatoid factor.
- Radiographic evidence of RA.

These symptoms can lead to deformities and the inability to continue performing daily tasks such as washing, dressing and the fulfilment of duties at work (Schneider *et al*, 2008). As it progresses, RA has also been found to have extra-articular effects (Clements, 2012; Symmons *et al*, 2000) such as:

- Nodules - a small swelling of aggregated cells.
- Pulmonary fibrosis – scarring of the lungs due to chronic inflammation.

- Peripheral neuropathy – numbness, weakness or loss of reflexes due to malfunctioning of nerves outside the spinal cord.

In 2010, the criteria for a positive diagnosis were reviewed by the ACR and the European League Against Rheumatism (EULAR) so as to make it easier to identify early RA and improve the rate of referrals from primary healthcare settings to rheumatologists (Figure 1) (Clements, 2012, p534). According to the new algorithmic criteria, patients who score a value greater than or equal to six can be classified as having a positive diagnosis for RA (Davies & Matteson, 2012). This algorithm is to be used only in patients who have clinical synovitis (swelling) in at least one joint, and have been ruled out from having other rheumatic or joint related diseases such as osteoarthritis and systemic lupus erythmatosus (Clements, 2012).

It has, however, been noted that it may take a number of years before health facilities worldwide are equipped with the necessary infrastructure to implement the new diagnostic criteria. South Africa is one such country where the infrastructure is not yet available to most of the population (Naidoo, 2012; Stuckler *et al*, 2011; Coovadia *et al*, 2009).

The ACR has also outlined criteria which are currently used to classify functional status of individuals with RA (Hochberg *et al*, 1992, pg 499). The four groups are used to describe the degree of disease progression by considering the extent of physical disability:

- Class I: Completely able to perform usual activities of daily living. (Self-care, vocational, and avocational).
- Class II: Able to perform usual self-care and vocational activities, but limited in avocational activities.
- Class III: Able to perform usual self-care activities, but limited in vocational and avocational activities.

- Class IV: Limited in ability to perform usual self-care, vocational, and avocational activities.

### Comparison between 1987 criteria and 2010 criteria for rheumatoid arthritis

1987 criteria	2010 criteria
<ul style="list-style-type: none"> <li>▪ Morning stiffness: Stiffness in or around the joint lasting for at least 1 hr</li> <li>▪ Arthritis of <math>\geq 3</math> joint areas: Evidence of soft tissue swelling or fluid observed by a physician</li> <li>▪ Arthritis of hand joints: Evidence of soft tissue swelling</li> <li>▪ Symmetric arthritis: Simultaneous involvement of the same joint areas</li> <li>▪ Rheumatoid nodules: Subcutaneous nodules over bony prominences or extensor surfaces or in juxta-articular regions observed by a physician</li> <li>▪ Serum RF: Demonstration of abnormal serum RF</li> <li>▪ Radiographic changes: Radiographic changes including erosion or bony decalcification</li> </ul>	<ul style="list-style-type: none"> <li>• Joint involvement               <ul style="list-style-type: none"> <li>• 1 large joint = 0 point</li> <li>• 2-10 large joints = 1 point</li> <li>• 1-3 small joints = 2 points</li> <li>• 4-10 small joints = 3 points</li> <li>• &gt;10 joints = 5 points</li> </ul> </li> <li>• Serologic tests               <ul style="list-style-type: none"> <li>• Negative RF and anti-CCP antibodies = 0 point</li> <li>• Weakly positive RF or anti-CCP = 2 points</li> <li>• Strongly positive RF or anti-CCP = 3 points</li> </ul> </li> <li>• Acute-phase reactants               <ul style="list-style-type: none"> <li>• Normal CRP and ESR = 0 point</li> <li>• Elevated CRP or ESR = 1 point</li> </ul> </li> <li>• Duration               <ul style="list-style-type: none"> <li>• &lt;6 weeks = 0 point</li> <li>• &gt;6 weeks = 1 point</li> </ul> </li> </ul>

Abbreviations: anti-CCP, anticyclic citrullinated peptide; CRP, C-reactive protein; ESR, erythrocyte sedimentation rate; RF, rheumatoid factor

Formulary/Source: Refs 4,5

Figure 1: Comparison between 1987 criteria and 2010 criteria for rheumatoid arthritis

(Reported in: Clements, 2012, p534)

## **TREATMENT FOR RHEUMATOID ARTHRITIS**

Fortunately, biomedical methods for managing the disease have been developed and are being utilized. Studies have shown that early and aggressive treatment with disease modifying anti-rheumatic drugs (DMARDs) can reduce inflammation and cause low disease activity and sometimes, remission where there are no clinical signs of inflammation (Davis & Matteson, 2012; Onysko & Burch, 2012; Hodkinson *et al*, 2011). It has also been proven that the use of these drugs, although they carry the risk of severe side effects such as gastrointestinal disturbances, myelosuppression and hepatotoxicity, are very effective in slowing disease progression and significantly improving the patient's health quality of life (Kumar *et al*, 2011; Schneider *et al*, 2008). For this reason, it is important that adherence to DMARD therapy be promoted and enhanced.

The treatment, however, as a function of the nature of the disease, has to be taken chronically. Adherence to treatment becomes exceptionally important for these patients who have been diagnosed with RA. Such patients are, usually from the point of diagnosis, expected to incorporate a drug regimen into their daily lives, for the rest of their lives. The introduction of chronic medication into a patient's life often means that new behavioural patterns need to be established but if the message is not, for any reason, accurately understood by the patient their well-being is further compromised (Morris & White, 2007). Chronic therapy can often be complex and require that the patient take a number of drugs at various times throughout the day (Toh *et al*, 2010). Along with the complexity of therapy, factors such as low income and co-morbid diseases have also been cited as factors that can make chronic therapy both overwhelming and confusing for newly diagnosed patients (Mishra *et al*, 2011).

The difficulty of incorporating a new drug regimen into their lives may be reduced if patients fully understand the reasons behind each drug



and how the drug is expected to improve their health or quality of living (Felzmann, 2012; Mir & Sheikh, 2010; Homer *et al*, 2009; Barford *et al*, 2006). This requires an accumulation of knowledge which can be received directly from healthcare providers or from information leaflets, package inserts or other sources of information. The problem with this process is that most sources that deal with medical or pharmacological concepts are written in biomedical jargon, a 'foreign language' to most lay people. Here, the role of the healthcare provider in communicating accurate information is absolutely essential in deciphering the concepts and explaining them in "bite-size chunks" to the patient (Barnett, 2007).

The quality of the relationship and effectiveness of communication between both parties has great bearing on patient perceptions and satisfaction. Studies have shown that where there is effective communication and a strong relationship with Healthcare providers, patients gain better understanding of their disease and its treatment, and as a result, begin to make better choices regarding their adherence to therapy (Neeman *et al*, 2012; Fakhr-Movahedi *et al*, 2011). It is also at this point that pharmacists can intervene and use their area of expertise to better the lives of people in their communities by being the source of accurate medicines information that is delivered in a manner which can be better understood by patients. Setter *et al* (2012) and Govender *et al* (2011) conducted studies which have proven that pharmacists' intervention, often in collaboration with other healthcare providers, can assist in patient education and contribute towards improved adherence rates.

A number of quantitative studies have investigated the activity or efficacy of specific drugs in RA management and how they affect patients' health related quality of life, such as those by Picchianti-Diamanti *et al* (2010) and Saevarsdottir *et al* (2011). Picchianti-Diamanti *et al* (2010) confirmed the efficacy of using the biological drug, etanercept, and how it can significantly reduce rheumatic disease

activity, thus improving health related quality of life. The study conducted by Saevarsdottir *et al* (2011) investigated the negative effects that cigarette smoking can have on the efficacy of prescribed RA therapy, and subsequently lead to more rapid disease progression. Both these studies contribute to the body of knowledge relating to RA and its treatment. There is, however, not enough research on adherence to RA chronic treatment as a whole. It is a disease that can greatly impact a patient's lifestyle and quality of life with the chronic pain and progressive loss of functionality of one's hands. These factors affect the individual, but RA also has the potential to place an extra burden on the health system. It has been found that patients with RA are almost twice as likely to be hospitalized for respiratory tract, skin and gastro-intestinal infections (Smitten *et al*, 2008; Doran *et al*, 2002). This is due to both the immunomodulatory effects of RA, and the use of immunosuppressive medication as treatment for it; a consequence that could lead to reduced faith in the medication and subsequent non-adherence.

Like most other chronic conditions, RA is a progressive disease. This means that with time, treatment has to be altered either by increasing dosages or by switching to other drugs. The next class of drugs in RA treatment, after those currently used in the public sector of South African health institutions, is the Biologicals. These drugs have been found to predispose patients to the risk of contracting Tuberculosis, and in some cases to reactivate chronic viral infections such as HIV (De Keyser, 2011; Gomez-Reino *et al*, 2003). In a country where TB and HIV/AIDS are already such a huge problem, it is imperative that we make efforts to avoid further infection. That can be aided if we can ensure better adherence to current RA medication, so as to prolong the time before which patients need to take Biologicals.

Adherence to treatment is strongly encouraged because there is greater

possibility for the patient's health related good quality of life to be improved. Non-adherence to RA treatment will result in increased disease progression and greater physical pain and disability to the patient (Hodkinson *et al*, 2011).

### **CONVENTIONAL MEDICINES USED IN THE TREATMENT OF RHEUMATOID ARTHRITIS**

Because RA is incurable, treatment for the condition focuses on the alleviation of symptoms and attempts to maintain functional status by slowing down the disease progression (Holtzman *et al*, 2004). There are four classes of drugs used in the treatment of RA:

1. Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)
2. Disease Modifying Anti-Rheumatic Drugs (DMARDs)
3. Glucocorticosteroids
4. Biologicals

These drugs are often used in various combinations to achieve two primary goals: relief of pain and inflammation, and slowing down the disease progression. By achieving these goals, the patient's quality of life can be improved and they can regain their independence (Davis & Matteson, 2012).

#### **Non-Steroidal Anti-Inflammatory Drugs**

NSAIDs are a class of drugs used in RA for their anti-inflammatory and analgesic properties. Thus, they will help to relieve the pain and inflammation associated with RA but have no effect on the disease activity (Onysko & Burch, 2012; Katzung, 2007)

In the inflammatory pathway, arachidonic acid is oxygenated by the cyclooxygenase (COX) enzyme to produce eicosanoids, a group of inflammatory mediators. NSAIDs inhibit the COX enzyme, thus down-

regulating the production of inflammatory mediators and relieving inflammation (Katzung, 2007).

The advantage of using NSAIDs is that pain relief occurs almost immediately. For this reason, NSAIDs have been used as monotherapy in the earliest stages of the disease to relieve patients of pain and inflammation where stronger drugs are not yet indicated. In later stages of the disease, NSAIDs will provide less relief to patients because of the extent of the inflammatory process.

NSAIDs are associated with side effects such as gastrointestinal disturbance and peptic ulceration. Hypersensitivity reactions have been known to cause effects such as bronchospasm, skin rashes and pruritis. In excessively high doses, NSAIDs can cause headaches, dizziness and renal and hepatic toxicity (Gibbon *et al*, 2008).

The most commonly used NSAIDs in RA are diclofenac and naproxen (*Table 1*).

#### *Disease-Modifying Anti-Rheumatic Drugs*

Unlike NSAIDs which are used for symptomatic relief, DMARDs are used for their immunomodulatory effects (Gibbon *et al*, 2008; Katzung, 2007). These agents slow down the disease progression, and have the ability to induce disease remission (Onysko & Burch, 2012). In accordance with the most recent ACR and EULAR guidelines, DMARDs are being prescribed as soon as there is a positive diagnosis of RA (Clements, 2012). The philosophy behind these guidelines is that early aggressive treatment will yield a better prognosis for RA patients (Davies & Matteson, 2012; Onysko & Burch, 2012).

By various means and pathways, these drugs inhibit the functioning of the immune system (Gibbon *et al*, 2008):

- Methotrexate inhibits the enzyme dihydrofolate reductase. This inhibits the synthesis of folic acid which is essential for the production of DNA precursors. This has a negative effect on lymphocyte and macrophage function, thus the immune response is reduced (Katzung, 2007). The drug is co-administered with folic acid to restore the deficiency it causes.
- Sulphasalazine is metabolised into sulphapyridine which is believed to be the compound responsible for its anti-rheumatic effect. It causes a reduction in immunoglobulins IgA and IgB, as well as rheumatoid factor production. Suppression of T-lymphocyte cells has also been noted (Katzung, 2007).
- Leflunomide's immunomodulatory effect comes from its inhibition of the synthesis of DNA precursor, pyrimidine. It is used predominantly in patients who are unresponsive to or cannot tolerate methotrexate (Gibbon *et al*, 2008).
- The mechanism of action of chloroquine's anti-inflammatory action remains unclear but it has been suggested that the drug suppresses T-lymphocyte responses, decreases lymphocyte chemotaxis (movement), and inhibits DNA and RNA synthesis (Katzung, 2007).

DMARDs are the most commonly used drugs to treat RA (Clements, 2012). The immunomodulatory effects, however, only become apparent after a period of six weeks to six months of treatment initiation (Katzung, 2007).

Because RA is an autoimmune condition, this class of drugs functions by suppressing the immune system and, therefore, hampering disease progression. As a result of the suppressed immune system, these drugs have an extensive side effect profile. DMARDs can cause headaches, nausea, myelosuppression, mucosal ulceration, hepatotoxicity and a variety of skin conditions (Gibbon *et al*, 2008; Katzung, 2007).

The most commonly used DMARDs are methotrexate, sulphasalazine, leflunomide and chloroquine (Buhroo & Baba, 2006; Maddison *et al*, 2005; Singh & Wangjam, 2001) (*Table 1*).

### Glucocorticosteroids

Glucocorticosteroids are used in conjunction with DMARD therapy. Glucocorticosteroids can be administered orally or as intra-articular injections (Gibbon *et al*, 2008). Oral prednisone, in low doses, can be given as long-term therapy to help in the rapid reduction of inflammation and for their mild immunosuppressant activity. Intra-articular glucocorticosteroids are administered directly into joints that flare markedly, in the opinion of the prescriber.

Glucocorticosteroids bind to specific receptors in cell nuclei. This receptor-glucocorticosteroid complex then binds to DNA sites, thus affecting gene transcription. This alteration of gene expression leads to suppression of many aspects of the inflammatory process such a prevention of formation of arachidonic acid (Gibbon *et al*, 2008). The effect anti-inflammatory effect of these drugs is not as rapid as that produced by NSAIDs but is usually more pronounced.

The side effects associated with glucocorticosteroids include peptic ulceration and osteoporosis.

The most commonly used glucocorticosteroid is prednisone (*Table 1*).

### Biologicals

Biologicals are used to treat active RA upon failure of combination DMARD therapy, or once patients can no longer tolerate the adverse effects of such therapy (Lopez-Olivio & Tayar, 2012). These drugs function by selectively blocking specific cytokines or immune system pathways to cause a reduction in inflammation and joint destruction.

Most notable are the drugs that inhibit tumour necrosis factor- $\alpha$  (TNF- $\alpha$ ), etanercept and Infliximab. Rituximab and Abatacept modulate B-lymphocytes and T-lymphocytes, respectively (Onysko & Burch, 2012). Because of their inhibitive effect on the inflammatory process, TNF- $\alpha$  inhibitors can greatly reduce the symptoms of RA, possibly leading to disease remission.

These drugs are the latest advancement in RA therapy and, as such, are very expensive. The cost of these drugs is one of their biggest drawbacks. In a country like South Africa, biological drugs are available predominantly in the private sector and only to a small fraction of patients in the public sector, usually to those participating in clinical trials.

The most common side effects associated with Biologicals are hypersensitivity and injection-site reactions (Lopez-Olivio & Tayar, 2012). They have also been found to increase the risk of contracting macrophage-dependent infections such as Tuberculosis and other upper respiratory tract infections. As a result, patients are screened for latent and active TB prior to the initiation of Biologic therapy (Lopez-Olivio & Tayar, 2012; Katzung, 2007).

The most commonly used Biologicals include etanercept, infliximab, rituximab and abatacept (Lopez-Olivio & Tayar, 2012) (*Table 1*).

*Table 1: Conventional drugs used in the management of RA*

Name of Drug	Dosage	Adverse Effects	Drug Interactions
<b>NSAIDS</b>			
Diclofenac	25-50mg 3 times daily, the lower range (75-100mg/day).	<u>Common:</u> Gastric effects, fluid and sodium retention, bronchospasm, skin rashes, oedema. <u>Uncommon:</u> CNS effects including headaches, drowsiness and depression, nephrotoxicity, renal insufficiency.	<u>Oral anticoagulants:</u> Enhanced risk of bleeding. <u>Other NSAIDs:</u> Additive adverse effects. <u>Glucocorticoids:</u> May enhance toxicity of both medicines. <u>Methotrexate:</u> Increased levels and toxicity of MTX. <u>Antihypertensives:</u> Efficacy of antihypertensives may be markedly attenuated.
Naproxen	Initially 250mg twice daily, increased if necessary to 500-1000mg/day in two divided doses. Minimum effective doses are used for maintenance.	Same as for diclofenac.	Same as for diclofenac.
<b>DMARDS</b>			
Methotrexate	7.5mg weekly (as single dose or 2.5mg 12 hourly for 3 doses), adjusted according to response, maximum 25 mg per week.	<u>Common:</u> Mouth ulceration and bleeding, skin rashes, headache, drowsiness, blurred vision. <u>Uncommon:</u> Interstitial	<u>Probenecid, aspirin and other NSAIDs:</u> Inhibit renal clearance of MTX, increasing toxicity risk. <u>Phenytoin, trimethoprim, co-</u>



Name of Drug	Dosage	Adverse Effects	Drug Interactions
		<p>preumonitis, bone marrow suppression, kidney and liver damage.</p> <p><i>*used with folic acid</i></p>	<p><u>trimoxazole and triamterene:</u> additive anti-folate activity, increased risk of methotrexate toxicity.</p> <p><u>Alcohol:</u> Enhances hepatotoxicity.</p> <p><u>Allupurinol:</u> Dose may need to be increased as MXT may increase serum uric acid concentrations.</p> <p><u>Anticoagulants:</u> MXT may inhibit clotting factor synthesis, monitor INR closely.</p> <p><u>Live virus vaccines:</u> Should be avoided due to immunosuppression.</p>
Sulphasalazine	500mg daily after food. May be increased by 500mg/day at weekly intervals until the maximum point of 4 tablets daily (2g) - 2 tablets twice daily.	<p><u>Common:</u> Headache, fever, loss of appetite, leucopenia, nausea, vomiting, diarrhoea, rashes, orange discolouration of urine.</p> <p><u>Uncommon:</u> Dizziness, anaemia, ringing of the ears, pseudomonas colitis, joint pain, pancreatitis, depression, shortness of breath, coughing, photosensitivity, hair loss, kidney damage.</p> <p><u>Rare:</u> SLE, hypoglycaemic effects,</p>	<p><u>Digoxin and Folate:</u> Absorption of sulphasalazine is reduced.</p> <p><u>Iron:</u> Chelating occurs and absorption is hampered.</p> <p><u>Methotrexate and phenytoin:</u> Their effect may be potentiated.</p> <p><u>Sulphonylureas:</u> Hypoglycaemic effects may be enhanced.</p> <p><u>Digoxin:</u> Potentiation of anticoagulation.</p>

Name of Drug	Dosage	Adverse Effects	Drug Interactions
Leflunomide	10-20mg daily;	<p>hypothyroidism.</p> <p><u>Common:</u> Diarrhoea, nausea, vomiting, abdominal pain, weight loss, mouth ulcers, headache, dizziness, rashes, hair loss.</p> <p><u>Uncommon:</u> Anaemia, thrombocytopenia, urticaria, raised potassium levels.</p> <p><u>Rare:</u> Hepatitis, agranulocytosis, anaphylaxis, toxic epidermal necrolysis, Stevens-Johnson Syndrome.</p>	
Chloroquine	150-300mg daily initially, reduced to 150mg after 7-10 days. After remission is obtained a 5-days-a-week regimen should be attempted. Recommended dose 2.4mg/kg.	<p><u>Common:</u> GIT effects, rashes, headaches, dizziness, blurred vision</p> <p><u>Rare:</u> Ototoxicity, blood dyscrasias, cardiovascular effects, neuropsychiatric effects.</p>	<p><u>Antacids (magnesium trisilicate, kaolin):</u> Absorption of chloroquine may be reduced.</p> <p><u>Cimetidine:</u> Metabolism and elimination of chloroquine may be reduced.</p> <p><u>Co-trimoxazole and other sulphonamides:</u> Increased risk of potentially fatal skin reactions.</p> <p><u>Mefloquine:</u> Increased risk of neurotoxicity and cardiotoxicity.</p>

Name of Drug	Dosage	Adverse Effects	Drug Interactions
<b>CORTICOSTEROIDS</b>			
Prednisone	<p>Intra-articular: 0.5-3ml(2-12mg); repeated as needed, but not more than 4 per year to a weight-bearing joint.</p> <p>Oral: 5-60 mg daily. Initial control may require high doses which must be reduced gradually to the lowest effective dose for maintenance.</p>	<p>Long term use may cause adrenal atrophy and inadequate corticosteroid secretion in response to stress.</p> <p>Musculoskeletal effects are main osteoporosis and proximal myopathy.</p> <p>Other effects include GIT disturbances, glaucoma and thrombocytosis.</p>	<p><u>NSAIDs</u>: Risk of peptic ulceration is increased.</p> <p><u>Hepatic enzyme inducing agents</u>: Corticosteroid therapy is diminished; dose may need to be increased.</p> <p><u>Insulin and oral anti-diabetic agents</u>: Dosage adjustment may be needed when steroid therapy is initiated or stopped.</p>
<b>BIOLOGICALS</b>			
Etanercept	25 mg twice weekly or 50 mg weekly, subcutaneous.	<p><u>Common</u>: Injection-site reactions, infusion reactions, serious bacterial and fungal infections, TB reactivation, possible increased risk of malignancy.</p> <p>Also causes nausea, diarrhoea, abdominal pains and headaches.</p> <p><u>Uncommon</u>: Bacterial infection, unusual infections, optic neuritis or Multiple Sclerosis, nerve disorders, worsening of Chronic Heart Failure.</p>	<p><u>Biologicals</u>: Concomitant use with other biologicals may lead to increased risk of serious infection due to excessive bone marrow suppression.</p>

Name of Drug	Dosage	Adverse Effects	Drug Interactions
Infliximab	3 mg/kg infusion at wk 0, 2, 6, and every 8 weeks (must be with methotrexate).	<u>Common:</u> Infusion reactions, upper respiratory infections. <u>Uncommon:</u> Anaphylaxis, bacterial infection, unusual infections, optic neuritis or Multiple Sclerosis, nerve, disorders, worsening of Chronic Heart Failure.	<u>Biologicals:</u> Concomitant use with other biologicals may lead to increased risk of serious infection due to excessive bone marrow suppression. <u>Drugs susceptible to cytochrome P450 enzyme metabolism:</u> Modulation of cytochrome P450 isozymes can alter the clearance rates of susceptible drugs.
Rituximab	1,000 mg IV on days 1 and 15.	<u>Common:</u> Hypertension, nausea, upper respiratory tract infections, arthralgia, pyrexia, pruritis. <u>Uncommon:</u> Infusion reactions, serious infections, and cardiovascular events, tumour lysis syndrome, severe mucocutaneous reactions, progressive multifocal leukoencephalopathy, hepatitis B virus reactivation, fatal renal toxicity, bowel obstruction and perforation.	<u>Biologicals:</u> Concomitant use with other biologicals may lead to increased risk of serious infection due to excessive bone marrow suppression. <u>Drugs susceptible to cytochrome P450 enzyme metabolism:</u> Modulation of cytochrome P450 isozymes can alter the clearance rates of susceptible drugs.

Name of Drug	Dosage	Adverse Effects	Drug Interactions
Abatacept	500-1,000 mg IV at 0, 2, and 4 weeks, then every 4 weeks 125 mg SC weekly after 1IV loading dose.	<u>Common:</u> Headache, upper respiratory tract infections, sore throat, and nausea. <u>Uncommon:</u> Serious infections, hypersensitivity reactions, hepatitis B virus reactivation, respiratory problems in patients with chronic obstructive pulmonary disease, cancer.	<u>Biologicals:</u> Concomitant use with other biologicals may lead to increased risk of serious infection due to excessive bone marrow suppression.

*(Summarised from: Zhou & Mascelli, 2011; Gibbon, 2008; Katzung, 2007)*

## **COMPLEMENTARY MEDICINES USED IN THE TREATMENT OF RHEUMATOID ARTHRITIS**

### **Traditional Medicines**

In 2008, Day & Gray stated that approximately 70% to 80% of South Africans consult with traditional healers before consulting with biomedical doctors. Having such a large portion of the population subscribing to tradition medicine coincides with an early study by Kale (1995) which stated that traditional healers in this country run a healthcare system parallel to that which includes biomedical doctors. These two health systems, although almost equally used, have very different approaches.

A benefit of modern science is that it is generally better researched and documented than traditional medicines. Treatment is, for the most part, standardised and practitioners are trained via a rigid system to ensure that all licensed health practitioners are capable of assisting patients with their health needs. However, in a country as culturally diverse as South Africa, much of the population has a strong rooted belief in traditional or complementary medicine and does not only access biomedical health practices. The biggest advantage that traditional healers have over modern doctors, as documented by Kale (1995), is that they are an integral part of the communities that they serve and that they know the ways of the people. The disadvantage, however, is the mystique surrounding traditional health practices. The healers are often very secretive about their methods because their practices are rooted in the spiritual realm and are not to be shared with outsiders. Thus, there is poor documentation of policies and the remedies used. The lack of a standardised system has left a fissure for charlatans who do not have the age-old knowledge that legitimate healers have, and thus it is not possible to keep track of the contents of many traditional remedies and medicines being sold to the public.

Legg (2010) described the experiences of aphasia patients living in Khayelitsha in the Western Cape who had consulted with traditional healers and herbalist. These patients were at times made to pay exorbitant fees for the promise of a cure for their condition. The patients reported how they would continue to use the treatment provided by the traditional healers even though they were experiencing no improvements in their health, because they were still hopeful that they may be cured. Such cases can be seen as examples of areas where patients' desires for improved quality of life may be exploited and taken advantage of.

In a study conducted by de Andrade (2011), it was suggested that there needs to be open communication between traditional healers and conventional healthcare providers in order for them to learn from each other. This may help to provide more effective medical interventions to patients seeking help.

The use of alternative and complementary medicines has been found to contribute to low levels of adherence in patients on chronic medication (Krousel-Wood *et al*, 2010). South Africa is one such country where a considerable number of people access therapies such as traditional African medicines, aromatherapy and ayurveda (Legg, 2010; Babb *et al*, 2007; Commey, 2004; Peltzer *et al*, 2008; Shuster *et al*, 2008). The various compounds in these alternative medicines have the potential to chemically react with conventional medicines and thus alter the concentrations necessary to achieve desired clinical outcomes. It is thus important that patients are counselled about the concurrent use of these medicines and how they can interact with their prescribed regimen. Counselling may help to also improve healthcare providers' knowledge of the belief systems of patients with regards to perceived causes and cures of disease (Park, 2002). Such elucidation could help towards improving the rate of adherence by offering an opportunity for clarification of misconceptions.

### Herbal Remedies

A study by Kaur *et al* (2012) stated that the extensive side effect profiles of conventional medicines have increased the chances of patients seeking herbal remedies as treatment for RA. In the same study, a number of common plants and herbs are listed for their anti-rheumatic activity (*Table 2*).

*Table 2: Common plants and herbs used in the treatment of Rheumatoid Arthritis (summarised from Kaur et al, 2012)*

<b>PLANT</b>	<b>ACTIVITY AGAINST RHEUMATOID ARTHRITIS</b>
Aloe vera	The anti-arthritis properties of the Aloe vera plant can be attributed to the anthraquinone compound. Topical application of the plant extract caused marked anti-inflammatory effects.
Ginger	Ginger extracts can be used to treat the nausea and vomiting that are side effects of conventional medicines. Ginger oil is also a powerful anti-inflammatory agent.
Green Tea	Green tea has been found to inhibit inflammatory mediators such as COX-2 and TNF- $\alpha$ .
Turmeric	Extracts from the turmeric plant have been found to inhibit inflammation in both the acute and chronic phases of arthritis.

These are common plants that are widely accessible to the public. The biggest problem regarding their usage is the lack of information about their interactions with conventional RA medication and how that may affect the overall health of patients.



## **NON-MEDICINAL TREATMENT FOR RHEUMATOID ARTHRITIS**

As previously stated, RA is a disease that can cause disabilities and affect one's ability to move and perform daily tasks (Picchianti-Diamanti *et al*, 2010). Medication can be prescribed by physicians and rheumatologists to treat the disease, but other health professionals can also use their fields of expertise to assist RA patients. Physiotherapists and Occupational therapists are often invited onto the team of health workers responsible for assisting RA patients. This collaborative approach by various health professionals has been found to be beneficial in providing a more holistic treatment plan for patients (Swann, 2011).

“Exercise” as defined by Eurenus *et al* (2005, p48), is “planned, structured and repetitive bodily movement done to improve or maintain one or more components of physical fitness”. In recent years, studies have shown that a well designed and controlled exercise regimen can serve to improve the health related quality of life of RA patients because the activity helps to relieve stiffness and improve muscle strength without increasing disease activity (de Jong *et al*, 2003; Stenstrom & Minor, 2003). The increased mobility that can be achieved with aerobic or water exercises has also been found to improve the emotional health of patients with severe disease as they gain the confidence to perform daily tasks again (Stenstrom & Minor, 2003). Physiotherapists are health professionals who have the expertise to design exercise programmes that can cater to the specific needs of RA patients. As a result, rheumatologists and physicians can consult more with physiotherapists with the aim of better assisting RA patients.

Occupational Therapists are utilised in the team of health workers to design tools for RA patients that make it easier to manage daily tasks when they can no longer manage the tasks unassisted (Swann, 2011). These assistive tools can be designed to simplify a variety of tasks from unlocking doors to assisting with matters of personal hygiene (*Table 3*)

(Swann, 2011, p80). The assistive tools also serve to help patients regain their independence.

**Table 3: Assistive solutions to problems associated with Rheumatoid Arthritis (Reported in: Swann, 2011, p80)**

<b>Assistive solutions to problems associated with rheumatoid arthritis</b>		
<b>Problem</b>	<b>Equipment/item</b>	<b>Adaptation</b>
<b>General household tasks</b>		
Unlocking door	Key turner	Key fob opening
Operating round knobs on doors		Replace with lever handle
Operating lever door handle	Loop attached to door handle	Replace with handle to be operated by forearm Automatic door opening
Switching on light switches	Long-handled wooden dowel	Rocker plate Sensor lights Touch lights
Operating pull cord light switches	Enlarged end-pulls	As above
Turning taps	Tap turners	Lever taps or lever tap conversion kit Sensor operated taps
Making hot drinks	Lightweight kettle Kettle tipper	
Lifting pans	Steamer or cooking basket	
Writing	Felt-tipped or lightweight pens Large barrelled pens or pen grips	
Reading	Book holders or electronic books	
Telephone and mobile	Hands-free phone with speed dialling for frequently-used numbers Big-button phones	
<b>Mobility</b>		
Rising from chair	Chair blocks or higher seated chair Standing frame Riser seat unit	Wall-fixed handrails
Holding walking stick	Fischer-type handle	
<b>Personal care</b>		
Flushing toilet	Extended lever handle	Wash-dry toilet Automatic flush
Using toilet paper	Interleaved paper Toilet paper holder	Wash-dry toilet
Rising from toilet	Raised seat Toilet seat with frame	Handrails Higher seated toilet
Feeding	Padded handles Straight-sided plates and bowls	
Drinking	Two-handled cups and mugs Rubber bottle openers	
Washing	Long-handled items Washing mitts	
Bathing	Bath aids Bath lifter	Shower over bath Level access shower
Hair management	Long-handled combs and brushes Hairdryer stand	
Dressing	Zip pulls Button hooks	

## **LEGAL ASPECTS OF MEDICATION**

The term 'medicine' or 'drug' is used to describe "the generic name of any substance used for the prevention, diagnosis and treatment of diagnosed disease and also for the relief of symptoms. The term 'prescribed drug' describes such usage" (Brooker, 2003, p94). The term 'drug' is generally used, by the public, to describe substances with negative connotations such as those used illegally in addiction cases. Both terms, however, are used interchangeably by health practitioners.

In South Africa, the Medicines Control Council (MCC) is responsible for the control, classification and registration of medicines, in accordance with section 5 of the Medicines and Related Substances Act 101 of 1965, as amended (hereafter referred to as the Medicines Act). The MCC classifies drugs into various schedules according to their risk-benefit relationship. The scheduling system is a means to regulate public access to medication and an attempt by government to prevent the misuse of drug substances. This process is informed by the rulings of the International Narcotics Control Board (INCB) which legislates that drugs which are psycho-active or have "mind-altering" properties be allocated higher schedules such that they may be more strictly controlled and be less accessible to the general public. Drugs which are to be used for chronic conditions are given lower schedules as patients would need to have access to them on a more regular basis. The lowest schedules contain drugs which the general public can access fairly easily, without the much consultation with health practitioners (*Table 4*) (Medicines Act s22 (a) (iii-v)). The lower scheduled drugs are generally more accessible to the public and considered to be safer than those in higher schedules.

Although it is often accompanied by various lifestyle and non-medicinal advice, medication is the principal intervention introduced by healthcare providers as an aid to ill patients. It is consequently very important that medication is used aptly so as to attain the best possible clinical outcomes. This implies that the prescribing doctor has a certain

level of expectation that patient to whom the medication is prescribed will choose to adhere to the instructions of the prescription.

*Table 4: Summary of the South African drug scheduling regulations*

SCHEDULE	REGULATIONS
S0	Used in conditions where the public can self diagnose; can be sold to anybody and are usually freely available, in small quantities, on the shelves at retail outlets
<b>OVER THE COUNTER MEDICATION:</b> <i>These drugs are only available in pharmacies and may not be placed in front of the pharmacy counter. They may be purchased by anyone over the age of 12 and a doctor's prescription is not necessary.</i>	
S1	Generally self-prescribed by the user.
S2	Generally purchased after consultation and recommendation from a pharmacist.
<b>PRESCRIPTION ONLY MEDICATION:</b> <i>These drugs may only be purchased provided that there is a valid prescription from a doctor. They are to be kept in the pharmacy and not the OTC section. These drugs are more tightly controlled. They are often used chronically or in cases of infective diseases.</i>	
S3	May be repeated for a period of no more than 6 months. Predominantly used in chronic diseases of lifestyle.
S4	May be repeated for a period of no more than 6 months. Predominantly used in infective diseases.
S5	May be repeated for a period of no more than 6 months. Generally comprised of psycho-active drugs.
S6	May not be repeated, thus, a new prescription is required for each month of use. Each purchase needs to be recorded into a separate S6 book for record-keeping. Instructions on the prescription need to be written in both numbers and words
S7	Banned substances; narcotics. May not be sold by anyone.
S8	Upon special request, these drugs are supplied directly from the Director-General of the Dept of Health to the doctor treating the particular patient. Pharmacists generally have no interaction with these drugs

## CHAPTER THREE: LITERATURE REVIEW

### MEDICATION TAKING PRINCIPLES

Upon furnishing of the prescription, it is the expectation of the prescriber that the patient will follow the prescription so that their health concerns may be addressed; however, research has shown that 30-50% of prescribed medication is not taken as prescribed (Felzmann, 2012). This failure to take medication as prescribed may result in the exacerbation of the ailment and deterioration of the patient's health. The process of following prescribed instructions has been widely researched so as to efficiently address the possible harms that may result from not adhering to prescribed instructions (Cramm *et al*, 2010; Krousel-Wood *et al*, 2009; Ncama *et al*, 2008; McInerney *et al*, 2007). Although the relationship between taking medication and positive clinical outcomes is not directly proportional, it is a widely accepted notion, by healthcare providers, that the correct use of prescribed medication best potentiates the achievement of positive clinical outcomes. As a result, the principles governing medication taking have developed and become more sophisticated, and have focused on patient centeredness improved communication between both health providers and patients (Felzmann, 2012, Tay *et al*, 2011; Dowell *et al*, 2007) (*Figure 2*).

Traditionally, the term compliance was used to describe medication taking. This term has gradually been phased out of use because of the negative connotations associated with it (Felzmann, 2012). Compliance enforces a patriarchal paradigm where patients are simply expected to do as they are told and not have an opinion about their treatment. It implies that the prescriber has a better knowledge of patient needs than the patients themselves. The approach, therefore, is not centred on the health related needs and desired outcomes of the patients (Dowell *et al*, 2007). Non-compliance, therefore, was associated with rebellion, apathy and disobedience on the part of the patient regarding their

health. This concept also imposed the societal hierarchy that healthcare providers were superior to patients and were thus not to be questioned regarding their medical opinions. As a result of these connotations, compliance greatly hampered the relationship between patients and health workers, and made communication difficult. For these reasons, compliance is a principle used less frequently in medical practice today.

In attempts to improve communication and forge better relationships between patients and healthcare providers, the principle of adherence was adopted. Initially, it also focused on the patient following the instructions of the healthcare provider. If the patient chose to follow the instructions, they were considered adherent, but were non-adherent if the instructions were not followed. This concept of adherence was revised by Kim *et al* (2007). Adherence became a concept which involved an understanding, by the patient, of the health suggestions made by the healthcare provider, and their subsequent ability or willingness to take the medication exactly as prescribed. It involved the manner in which patients administered their drugs with respect to the manner intended by the healthcare provider. This did not mean that the views or opinions of the patient were being disregarded, but rather that the patient had a choice as to whether they would adhere to prescribed treatment or not, for whatever reason (Kim *et al*, 2007).

COMPLIANCE	ADHERENCE	CONCORDANCE
<ul style="list-style-type: none"> <li>• Patriarchal paradigm</li> <li>• Assumed that the patients need not have an opinion on their treatment, and health workers were not to be questioned.</li> <li>• Non-compliance was associated with patient apathy and rebellion.</li> <li>• Made communication difficult.</li> </ul>	<ul style="list-style-type: none"> <li>• Involves patients understanding of their medication.</li> <li>• Gives patients the choice of whether to follow the the prescription or not.</li> <li>• Focuses on improved patient-provider communication.</li> <li>• Shares the responsibility of clinical outcomes.</li> </ul>	<ul style="list-style-type: none"> <li>• Newly accepted gold standard.</li> <li>• Reinforces the autonomy of patients.</li> <li>• Involves shared decision making between patients and healthcare providers.</li> <li>• Required that patients be adequately informed and educated about health practices.</li> <li>• Incorporates the desired treatment goals of the patient.</li> </ul>

*Figure2: Summary of the developments in medication taking principles*

*(Summarized from: Felzmann, 2012 and Kim et al, 2011)*

The achievement of adherence is central to the success of chronic drug treatment. Kim *et al* (2007) looked at whether non-adherence to chronic hypertension medication was unintentional or intentional, citing reasons such as forgetting to take medication or deeming it unnecessary, respectively. Unintentional reasons suggest that non-adherence was not always an indication of the patient being irresponsible but possibly that they needed some kind of reinforcement to assist them with their regimen. Thus, the concept put less responsibility on the patient to see to it that their medication was taken as prescribed. Shared responsibility was instead placed on both the patient and the health provider to ensure the prescription was adhered to. More studies were conducted which asserted the findings of Kim *et al* (2007). They proved that it was important that more efforts were made to improve communication between patients and health providers, and encourage the development of relationships between



them so that the probability of achieving adherence could increase (Mir & Sheikh, 2010; Homer *et al*, 2009; Barford *et al*, 2006).

In more recent years, the concept of concordance was introduced and is now being accepted as the new “gold standard” of medication taking (Felzmann, 2012, p406). This principle describes the process of shared decision making between the patient and the health worker. It reinforces the autonomy of patients and suggests that the patient ought to have greater input in terms of their treatment and the desired clinical outcomes (Dowell *et al*, 2007). This principle assumes that the patient is educated and adequately informed about their disease and the relevant health practices and they can thus contribute towards the decisions made regarding therapeutic interventions. Ideally, concordance should be the principle adopted in all cases, however not all countries, South Africa included, can incorporate it into their health policies yet. This is because the socio-economic issues surrounding health practice, and other issues such as language barriers and low levels of literacy and education, render the majority of South African citizens unable to fully or effectively participate in the decision-making process (Banerjee & Sanyal, 2012). It is for this reason that this study focuses on adherence and not concordance.

For the purpose of this study, adherence will be defined as the ability or willingness of the patient to take medication exactly as prescribed, without the exclusion of prescribed drugs, nor the inclusion of non-prescribed drugs. This definition has been chosen because in both cases, there exists the possibility of treatment failure. The exclusion of prescribed drugs may lead to treatment failure by virtue of drug concentration levels in the body being lower than intended by the prescriber, while the addition of non-prescribed drugs to the regimen may result in chemical drug interactions with the additional drug that may also alter the desired drug concentration levels.

## **THE SOUTH AFRICAN HEALTHCARE SYSTEM**

During apartheid, the South African government provided “world class [health] care for White elites” and sub-standard care for the Black majority (Stuckler *et al*, 2010, p165). This means that when the new democratic government was instated in 1994, they inherited an innately unequal health system. Policies were drafted to address the inequities of the past and to ensure redistribution of health services and infrastructure.

Through its policies, the new government was been able to overcome some of the inequities created by the apartheid government (Harrison, 2009). The implementation of the Essential Drugs programme and the provision of free primary healthcare to the population have ensured that the previously disadvantaged majorities have improved access to healthcare. The immunisation programme has also been improved. The new government has also attempted to improve the infrastructure of clinics and hospitals. Unfortunately, studies have shown that the overall implementation of the legislated policies has been fairly poor and that the inequities of the past have not yet been fully addressed (Stuckler *et al*, 2010; Coovadia *et al*, 2009; Harrison, 2009).

The South African health system exists within a very complex context. There are a number of challenges that need to be overcome in order for the health system to be improved, so that the country’s entire population can have access to good quality healthcare. One of the challenges facing the health system is the disease burden. Naidoo (2012) and Coovadia *et al* (2009) have described the following issues as the biggest contributors to this burden:

- HIV/AIDS and TB.
- Poverty-related diseases (malnutrition; cholera).
- Maternal and childhood diseases.
- Non-communicable diseases.

- Violence and injuries.

The current health system is unable to adequately address this burden because of a lack of healthcare personnel and the necessary infrastructure (Naidoo, 2012; Harrison, 2009). Stuckler *et al* (2010) report that a tough economic climate has limited the resources and infrastructure that the government can provide to the South African population. This lack of funding, together with insufficient leadership and poor management of available funds has exacerbated the problem (Stuckler *et al*, 2010; Harrison, 2009). As a result of the burdensome public health system, morale amongst health workers has been low.

Limited resources in the public health system has also been identified as a reason why health personnel are moving into the private health sector where there are better incentives (Harrison, 2009). The private sector has better infrastructure and more funding which means better remuneration for healthcare providers. The movement into the private sector further compromises the public health sector as it increases the ratio between the number of patients and the available health providers. This means that public healthcare facilities are generally understaffed and poorly resourced which makes it even more difficult to provide good quality healthcare services.

Apart from the systemic issues in the public health system, the socio-economic and cultural context within the healthcare system can also make it difficult to provide good quality services. The public health sector caters to approximately 84% of the South African population (Naidoo, 2012). This demographic includes the most impoverished and illiterate members of the population. Thus, issues such as language barriers between health providers and patients can make communication difficult between these parties. Cultural differences can also make it difficult to achieve mutual understanding.

Financially, Stuckler *et al* (2010) describe a situation where government funding is consistent with the inverse care law, where the areas with the greatest healthcare needs, such as the rural parts of the country, received the fewest healthcare resources. This is another example wherein the positive policies of redistributing healthcare resources and eradicating the inequities of the past were poorly implemented. This kind of financial distribution only serves to increase the inequities between rural and urban South Africa.

The literature shows that although some positive changes have occurred within the public healthcare system, the negative aspects of public healthcare still overshadow them.

#### **ADHERENCE IN SOUTH AFRICA**

Many of the studies concerning adherence in the South African setting have involved adherence to treatment in patients with communicable diseases like tuberculosis (TB) and HIV/AIDS (Cramm *et al*, 2010; Ncama *et al*, 2008; Babb *et al*, 2007). Although these conditions will not be a focus in this study, they affect a large number of South Africans and adherence to treatment is crucial in preventing the spread of further infection and slowing disease progression.

Researchers such as Cramm *et al.* (2010) and McInerney and her colleagues (2007) focused less on the quantitative aspects of low treatment adherence but also sought to gain better understanding of the root of the problem through employing qualitative methodology. In 2008, a study by Ncama *et al* was published in which the social aspect of adherence was investigated with regards to patients on antiretroviral therapy (ART). The presence of social stigma and fear of being ostracized are factors which need to be addressed when dealing with patients as they can affect the patient's attitude towards their own medication. The rates of non-adherence can increase greatly if patients

do not have sufficient support. Although there are limits to how much healthcare providers can influence the opinions of the public, it is imperative that efforts be made to correct social stigma. Health education by pharmacists and other health professionals can help to improve the circumstances of patients on chronic medication. In the case of RA, the disability that results from the disease was cited as one of the reasons patients felt discouraged to fulfil social roles (Schneider *et al*, 2008).

The identification of patients' misinformed perspectives can be used as points of intervention to improve the way in which patients take their medicines and approach healthcare services. This is a principle that can be applied to any condition, including RA so as to identify areas where improvement initiatives can be directed.

As previously mentioned, the views and opinions of patients are critical when making clinical decisions (Kim *et al*, 2007; Osterberg & Blaschke, 2005; Gaudagnoli & Ward, 1998). Asking patients who have defaulted on treatment may also be a good way to determine why it is that they chose not to continue with treatment (Dahab *et al*, 2008). The problem with studies like the one conducted by Dahab *et al* (2008) is that the target group consists of people who may perhaps be beyond the point of intervention. Had the study been conducted earlier on in the course of these patients' illnesses, they may have been better helped. It is likely that the patients could have received assistance regarding their therapy soon enough to correct their misconceptions and have their medicine related problems addressed so that they could avoid defaulting on therapy which is what this study aims to do with RA patients.

The literature shows that in recent years, efforts have been made to investigate medication adherence of patients in South Africa (Cramm *et al*, 2010; Ncama *et al*, 2008; Babb *et al*, 2007). There is, however, still a need to conduct further research which focuses on understanding and

correcting the factors that perpetuate non-adherence as there could be factors that are yet to be discovered.

Studies conducted by Orrell *et al* (2003) and Mills *et al* (2006), in sub-Saharan Africa, on adherence to antiretroviral therapy suggest that poverty did not negatively affect adherence. However, poverty is only one aspect of the complex socio-economic and cultural context that exists in South Africa. As is indicated in the study conducted by Ware *et al* (2009), other factors such as the strength of social relationships with both health providers and other members of society may also influence adherence. It is for this reason that it is essential to continue to investigate such factors. It is important to direct some attention to other less investigated diseases such as RA as they do also affect members of the community, and the nature of each disease may contribute differently towards medication adherence.

### **MEASUREMENT OF ADHERENCE**

Adherence to treatment regimens can be measured in various ways including looking at clinical records or taking pill counts (Osterberg& Blaschke, 2005). Pharmacy refill data has been used to establish whether adherence is achieved, along with the aid of measures such as The Morisky Medication Adherence Scale (Morisky *et al*, 2008; Krousel-Wood *et al*, 2009; Al-Qazaz *et al*, 2010).

These methods are, however, quantitative in nature and rather impersonal and do not always take into account the perspective of the patient which can make them less reliable. Qualitative aspects such as the role, beliefs, desires and perceptions of patients are seldom included in the clinical decision-making process (Osterberg & Blaschke, 2005; Mir & Sheikh, 2010). The patient's right to self-determination should at all times be considered (Gaudagnoli& Ward, 1998).

Wagner *et al* (2005) and Mead & Bower (2000) have emphasized the issue of ensuring that the patient's right to agency and self-management is considered at all times by the team of health workers serving the patient. They found that having a patient-centred approach, where healthcare professionals work to support the patient and provide accurate medical advice regarding the chronic disease and its treatment, was the best way to ensure that patients became empowered and involved in the decision-making process on matters regarding their health.

The aim of therapy should be to improve the living circumstances of the patient and not to make this of lesser priority than the convenience of therapy for the health worker. Factors such as side effects, belief systems, cost and effects on lifestyle affect the degree to which the regimen can be integrated into the patients' lives, thus, can greatly influence whether adherence will be achieved or not (Hobden, 1998). It is also important to establish whether the patient understands the connection between the illness and the prescribed medication as such information can reiterate to them the importance of adherence to treatment.

The abovementioned factors have been identified as possible contributors of non-adherence in various communities. Whilst there have been adherence studies, very few approach this via a qualitative paradigm, and even fewer focus on RA. It is therefore essential that any factors jeopardizing the achievement of adherence with regards to this disease be investigated and, if possible, corrected so as to improve patient outcomes, which is what this study aims to do.

### **HEALTHCARE PROVIDER-PATIENT COMMUNICATION**

Tay *et al* (2011, p152) define effective communication as “a two-way process – sending the right message that is also being correctly received

and understood by the other person". Other studies have concurred with this definition and also discuss the importance of effective patient-provider communication in providing patients with good quality healthcare, and achieving medication adherence (Salt *et al*, 2012; Hemsley *et al*, 2011; Haskard-Zolnierek & DiMatteo, 2009).

Communication has been identified as an essential part of the patient-provider relationship because it is good communication that enables the sharing of both verbal and non-verbal information relating to the health concerns of the patients and the professional opinions of the healthcare provider (Tay *et al*, 2011; Haskard-Zolnierek & DiMatteo, 2009). Effective communication has also been identified as a catalyst for patient-provider relationships where patients are empowered to ask questions and give their input regarding their health, thus enabling them to participate in the decision making process when identifying solutions relating to their health related problems (Neeman *et al*, 2012; Salt *et al*, 2012). Communication increases the understanding of both the patient and healthcare provider and encourages the fostering of an open, supportive and empathetic environment where healthcare providers are able to see beyond just the biomedical problems and can thus treat the patients holistically (Haskard-Zolnierek & DiMatteo, 2009).



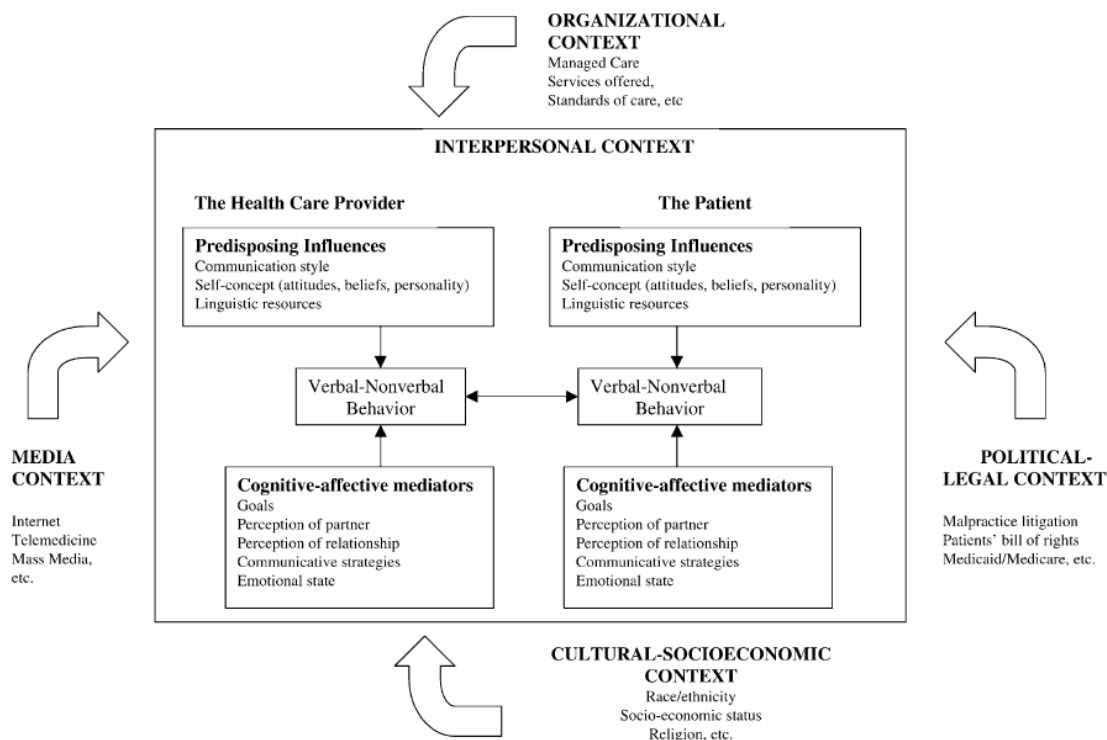


Figure3: Street's (2002, p202) ecological model of communication in medical encounters

Studies have found that the interpersonal relationship and interaction between the patient and healthcare provider are the factors that have the greatest effect on communication between both parties (Salt *et al*, 2012; Street Jr, 2002). This relationship, however, is a complex one because it exists within a myriad of contexts that influence both participants in the conversation, as described by Street's ecological model of communication in medical encounters (*Figure 3*) (2002, p202). In this model, external factors such as media, political, cultural, socio-economic and organizational influences are described as influencing the patient-provider relationship. Although these factors may not directly influence the subject of the patient-provider interactions, they do have a bearing on the interpersonal context, thus they can at times enhance or create barriers to effective communication.

In South Africa, research has been conducted regarding the cultural, socio-economic and organizational contexts (Levin 2007a; Levin, 2006).

These studies showed that because most patients in the public sector were not usually of the same socio-economic standing as doctors, and did not speak the same language as doctors, communication could be compromised. Often the biomedical terms used during consultations with doctors could not be adequately translated and thus there was a possibility of the terms carrying a different meaning to patients as opposed to the healthcare providers who understood medical jargon (Levin, 2007b). It was also noted that organizational and structural factors such as poor infrastructure, lack of equipment and inaccessibility of quality healthcare formed part of the external factors that may influence the interpersonal context (Levin, 2007a).

Good communication has also been cited as one of the major contributing factors towards the achieving of the patient-centred approach (Cousin *et al*, 2011). This study found that a good “caring communication style” approach by healthcare professionals conveyed a warm, empathetic and friendly message to patients that suggested to them that the healthcare providers were interested in helping them to help themselves. As a result, patients and healthcare providers could form a trusting and collaborative relationship that was centred on providing optimal care for patients. This kind of interaction between patients and the healthcare providers was found to encourage patients to be more assertive regarding their treatment plans and was a good predictor of patient satisfaction. Although communication about adherence can be difficult, the formation of such relationships between patients and healthcare providers can serve as a source of encouragement and contribute towards the achievement of medication adherence.

These studies serve to highlight the importance of effective communication in healthcare provider-patient interactions. Communication enhances the understanding of both patients and healthcare professionals, creating an environment where both parties

can be involved in the efforts to improve patient quality of life. Ultimately, good communication can increase adherence levels and should be encouraged in the South African healthcare setting.

This chapter has described the literature regarding the state of South Africa's health system, and the importance of adherence and the relationships between patients and healthcare providers. Much of the literature, however, focuses on communicable diseases such as HIV/AIDS and TB. There seems to be a lack of information regarding non-communicable diseases within the context of the South African healthcare system. RA is one such disease that has not been adequately described and researched in this country. The available adherence literature is also largely quantitative. This study therefore addresses these identified gaps in the literature through qualitatively investigating the complexities surrounding adherence to RA prescribed medication, as well as the living experiences and perspectives of patients affected by this disease.

## CHAPTER FOUR: METHODS

### AIM AND OBJECTIVES

This study was designed to identify the various issues that influence the adherence levels and medication taking practices of RA patients. In order to do this, it was decided that the focus of the study would be to investigate factors that may affect RA medication adherence. Thus the aim of the study was:

- To qualitatively determine factors affecting Rheumatoid Arthritis (RA) patients' adherence to chronic prescribed medication(s).

Three objectives were set that would make it possible to achieve the proposed aim:

- To establish what patients understand about the disease and its treatment.
- How they take their medication in relation to the instructions given by the prescribing doctor, and their understanding of dosage instructions.
- To determine contextual factors which may impact on patient understanding and adherence, as reported by patients.

### RESEARCH DESIGN

A qualitative approach was adopted to gain insight into patients' thoughts about their disease and its treatment, in order to understand the factors that influence their medication taking habits. In recent years, efforts have been made to investigate the medication adherence of patients in South Africa (McInerny *et al*, 2007; Ncama *et al*, 2008; Cramm *et al*, 2010). These studies had strong quantitative components but also began to explore the qualitative aspects of adherence. It was noted in the studies that there was still a need for more research regarding the understanding and addressing of factors that perpetuate

non-adherence. Qualitative methods have been successfully used in other adherence studies and found to be especially helpful in describing the adherence phenomenon as they reveal aspects which could not have been better explained by quantitative methods such as the emotional, cultural or personal experiences of patients (Kumar *et al*, 2011; Penn *et al*, 2011, Schneider *et al*, 2008). In all these studies, it was clear that the qualitative format allowed for a more in depth description of the patients' experience as it enabled patients to describe their living situations in their own words, whereas quantitative questionnaires seldom make allowances for such descriptions. Like these studies, this study focused particularly on the qualitative factors to gain better understanding of adherence in a local context. A phenomenological-type approach was employed, without imposing existing models, to report the exact accounts of the participants.

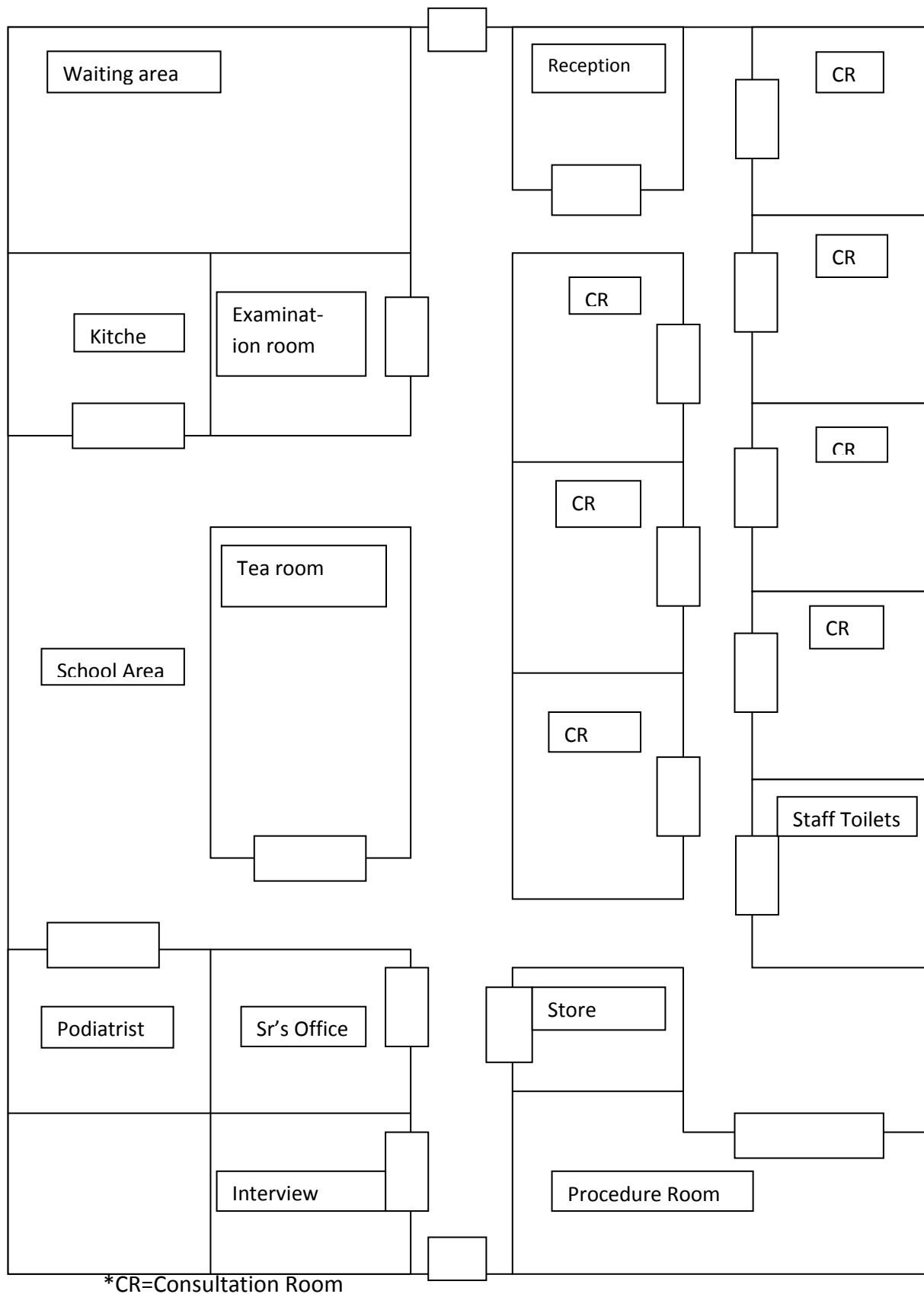
Three distinct methods of data collection were employed:

1. Video recorded interviews with patients and healthcare professionals.
2. Review of participants' medical records.
3. Ethnographic principles were used to observe the clinic and pharmacy setting, interactions between healthcare providers and patients.

### **RESEARCH SITE**

The study was conducted at a Rheumatology Clinic at a tertiary hospital in Gauteng (*Figure 4*). This site was chosen because it operates a discrete out-patient programme for patients diagnosed with RA. They hold weekly clinic days for RA patients which made it convenient for the interviewer to find suitable participants for the study, as opposed to a ward where it could not be predicted that RA patients would be present.

The clinic staff had a keen interest in the study and was very helpful throughout the data collection phase and contributed towards the successful execution of the study.



*Figure 4: Schematic diagram of the Rheumatology clinic where the study was conducted*

### Clinic staff

The clinic had one clerk who managed the reception area and was responsible for co-ordinating the patient appointments. She also allocated a number for each patient in the queue as they arrived for check-ups. There were two nurses at the clinic, a senior sister and staff nurse. The sister was responsible for overall supervision of the clinic which included administrative duties such as assisting patients to apply for disability grants and pension, as well as patient education and counselling. She provided counselling to all newly diagnosed patients and those who were identified as non-adherent to treatment. The staff nurse was responsible for checking and recording patients' blood pressure and glucose levels prior to them being seen by a doctor. Occasionally, there were student nurses who helped with these duties but they were not permanent members of the clinic staff. There was also a research nurse who worked exclusively with the various studies that the clinic conducted so she did not see regular patients who were not part of research studies.

The clinic had a complete team of seven doctors, three registrars and four consultants, but it was not often that all seven could be present at the clinic. During the course of the study, there was an average of 5 doctors at the clinic on RA clinic days. They consulted with patients, performed joint examinations and RA assessment tests, and prescribed medication as needed by patients. One of the consultants ran the "fast-queue". Patients who felt well and were not having problems with their medication, and who merely wanted their script renewed were invited to join the fast queue for one of their two to four clinic visits in a year. These patients would not have joint examinations and RA assessments performed on them.

Between them, the staff members saw 150-200 patients per clinic day at the time of data collection. At the time of data collection, the clinic was attended by over 2000 patients in total.



### Patient referral to the clinic

Patients experiencing symptoms of RA or joint pain had to first attend their local clinics or primary healthcare facilities. There they would be attended to by the clinic sister who may have treated them with analgesics, anti-inflammatory agents and oral steroids. Upon treatment failure, should the symptoms persist, these patients would be referred to the doctor at the primary healthcare clinic who would prescribe and administer intra-articular steroids alongside the oral agents. If treatment failed again and the doctor suspected an inflammatory arthritis, the patients were given a referral letter to the tertiary hospital where they were screened and sent to the RA clinic. This was a process which in some cases took many years and was detrimental to the patients' health as it resulted in disease progression and disability. As a result, the RA clinic staff did not always insist on a referral letter should patients find their own way to the clinic. Such patients were also screened and treated if found to have RA.

### Patient education and counselling

The senior sister, as previously stated, was responsible for all education initiatives. On clinic days, between 10:30 and 11:00 while the doctors took their tea break, she organised a group counselling session or "school" as referred to by the patients. The school team consisted of the senior sister, a physiotherapist, occupational therapist and podiatrist. These healthcare professionals offered advice related to their specialties, depending on queries raised by patients during the sessions. The physiotherapist taught patients about various physical exercises they could perform to help regain movement in their affected joints. The occupational therapists helped patients by creating tools that made it easier for patients to perform daily tasks such as opening taps or unbuttoning their clothing. The podiatrist educated patients about foot

care. The school had not yet enlisted the help of a pharmacist to address specific medicine related questions.

Because a different set of patients was seen at the clinic every week, the contents of the sessions were kept relatively similar so as to ensure that the information given to patients was as uniform as possible. Although attending the school sessions was highly recommended by the clinic staff, patients could decide not to attend. These patients would often leave the clinic for the duration of the school session and return once it was over. The patients who had their doctors' consultations before the school sessions could choose to stay and wait for the school session, but most of them often left the clinic immediately after their consultations to collect their medication at the pharmacy. As a result, only a fraction of the patients attending the clinic attend the school sessions as well.

## **PARTICIPANTS**

The patients who participated fulfilled the following criteria:

- They were 18 years or older.
- They had been diagnosed with Rheumatoid Arthritis according to the guidelines for diagnosis provided by Ncayiyana *et al* (2003) and, the American College of Rheumatology and EULAR (Clements, 2012)
- They were returning to the clinic for at least their second repeat visit after their diagnosis.
- Their clinical records were readily available and sufficiently complete.
- They were comfortable with and gave written consent to being video-recorded during the interview with the researcher.

The participants were purposively selected as it would have been impractical to employ random selection under the clinic circumstances. Since the doctors were more familiar with the patients than the researcher, a doctor from the clinic was asked to approach the patients.

This method of selection appeared to make patients more comfortable with the study as they recognised that the doctors supported it. Those who met the criteria and agreed to speak with the researcher then had the details of the study explained to them by the researcher, in their language of choice. Patients who agreed to participate were given lunch packs containing a sandwich, fruit juice and a small snack, after the interviews and prior to their consultations with a doctor. The lunch packs were a small token of appreciation to the patients for giving of their time to participate in the study as they had not received prior warning about the study and their participation meant spending additional time at the clinic.

The number of participants required per clinic day was pre-determined by the researcher (no more than five patients a day) and expressed to a doctor who approached potential participants to inform them about the study being conducted. Interested patients were then referred to the researcher who gave a verbal explanation of the study in greater detail to the group of potential participants. Upon providing verbal consent, the participants were individually taken into the interview room. Here, they were able to direct questions to the researcher, if necessary, and give written consent allowing the researcher to access their hospital records and to video-record the interview sessions. There was only one patient who was asked to participate and declined. She stated that she was in too much pain to walk to the interview room.

In the interview room, copies of the patients' records were made and the video-recorded interviews were conducted in the language of the participant's preference. Each interview lasted approximately 20 minutes and no more than five interviews were conducted per clinic day.

The researcher was cognisant of the fact that the patients may have felt coerced to participate when being approached by the doctor. For this

reason, the researcher gave each participant the opportunity to withdraw their participation during the verbal explanation of the study, and prior to them signing the consent form. Participants also had the opportunity to withdraw their participation before the video camera was switched on. It was also noted that knowledge of the lunch packs may have motivated patients to participate in the study. To prevent this, the lunch packs were brought into the interview room when the clinic opened, before most of the patients had arrived. Patients were thus unaware of the lunch packs until the day's participants had been selected and interviews had begun.

Patients who were classified as Functional level IV or severely disabled by RA (Hochberg *et al*, 1992) were not approached to participate so as not to inconvenience them with unnecessary movement to the interview room.

A total of 20 participants were interviewed but findings from only 18 were used in the analysis phase (*Table 5*). It was discovered after the interviews, while reviewing the patient records that one participant was attending the clinic for the first time, and the other did not have a positive diagnosis for RA at the time of the interview. These two patients were, thus, excluded from the study. Their exclusion did not disadvantage the study in any way as data saturation had been achieved prior to their involvement in the study.

*Table 5: Patient demographics*

<b>CODE</b>	<b>AGE</b>	<b>GENDER</b>	<b>DIAGNOSIS</b>	<b>HOME LANGUAGE</b>	<b>EDUCATION LEVEL</b>	<b>EMPLOYMENT STATUS</b>
<b>P1</b>	54	F	RA	ZULU	Grade 10	Fruit & Veg packer
<b>P2</b>	69	F	RA, DM, HT	XHOSA	Grade 4	Unemployed
<b>P3</b>	73	F	RA, HT	SOTHO	Grade 6	Pensioner
<b>P4</b>	40	F	RA	TSWANA	Tertiary	Unemployed
<b>P5</b>	57	F	RA, HT, Ch	ENGLISH	Matric	Unemployed
<b>P6</b>	66	F	RA, DM, HT	TSWANA	Grade 9	Pensioner
<b>P7</b>	44	F	RA, HT	ZULU	Matric	Unemployed
<b>P8</b>	64	F	RA	ZULU	Grade 8	Pensioner
<b>P9</b>	23	F	RA	SOTHO	Matric	Waitress
<b>P10</b>	60	F	RA, HT	TSONGA	Grade 8	Unemployed
<b>P11</b>	27	F	RA	XHOSA	Tertiary	Admin clerk
<b>P12</b>	76	F	RA, HT	TSWANA	Grade 10	Pensioner
<b>P13</b>	59	F	RA, HT	TSWANA	Grade 10	Unemployed
<b>P14</b>	46	F	RA	SOTHO	Matric	Unemployed
<b>P15</b>	57	F	RA, DM, HT, Ch	SOTHO	Grade 10	Unemployed
<b>P16</b>	59	F	RA, EP, HT, Allergy	TSWANA	Grade 8	Pensioner
<b>P18</b>	49	F	RA, HIV	PEDI	Grade 11	Unemployed
<b>P20</b>	48	F	RA	ENGLISH	Grade 11	Labeller

\*HT=Hypertension; DM=Diabetes Mellitus; EP=Epilepsy; Ch=Hyperlipidaemia

### **PILOT STUDY**

Three participants, who met the inclusion criteria, were interviewed as part of the pilot study in order to gauge the effectiveness of the interview schedule and the clarity of the questions. It was found that

the interview schedule was suitable for the study and only one extra question was added as a result of the pilot study (*Appendix A*). As suggested by the University Ethics Committee, findings from the pilot study were used in the data analysis because the participants met the stipulated criteria and no major changes were made to the interview schedule.

## **DATA COLLECTION**

Data collection took place over a period of six weeks. This allowed the researcher to collect data from a few participants at a time and spend time observing the weekly routine at the clinic. Thus, the researcher became familiar with the clinic and the staff, giving a more accurate perception of the clinic context.

### **Video-recorded interviews**

The primary mode of data collection was the patient interviews which were conducted in a private room on the far end of the clinic where other patients, and noise from the queue and registration area would not cause any interference.

Semi-structured interview schedules were used in order to explore the participants' perceptions. The questions in the interview schedule were adapted from the Morisky Medication Adherence Scale which has been described as a valid and reliable measure of assessing medication adherence (*Appendix B*) (Al-Qazaz *et al*, 2010; Morisky *et al*, 2008). The results reported in the study by Kumar *et al* (2011) were also used to derive questions. The interview schedules consisted of a variety of open-ended questions about their understanding of their chronic condition, medication, and its impact on their lifestyle (*Appendix A*). This approach was selected as it allowed for variations in the proposed questions, depending on the issues raised during each interview (Murray & Rhodes, 2005). This proved necessary as each participant had their own story to

tell and as a result, the interviewer had to further explore the various issues raised during these interactions. The ability to probe and ask further questions of the participants allowed for better clarification of their statements to the interviewer. It also allowed for patients to ask questions regarding the intended meaning of the research questions. As such, communication between both parties was enhanced by the nature of the interview schedule. Such clarifications may not have been possible had the interview schedule contained closed ended questions.

The interviews were video-recorded as it was anticipated that the participants would use their medication containers as props during interviews, as used in previous studies such as one conducted by Watermeyer & Penn (2009). Video-recording was also used as it would allow for the researcher to focus more on the conversation with participant, whereas traditional audio-recording would have required the researcher to split concentration between the conversation and noting down all the visual aspects of the interview. Such distractions could have compromised the communication between the participants and the interviewer which could ultimately have negatively affected the findings of the study. In recent years, video-recordings have been used in qualitative medical studies and found to produce findings that were superior to those where audio-recordings were used (Bahl *et al*, 2010; Ozcakar *et al*, 2009). Video-recording also allows for more comprehensive analysis of data during the analysis phase as the video tapes were an accurate depiction of the interview interactions (Penn *et al*, 2011). However, despite anticipating the potential role of props during the interviews, this did not happen, as most of the patients did not bring their medication and were able to easily recall the names of their medication(s).

The interviews were conducted in the home language of the participants (usually Sesotho and IsiZulu). The researcher was fluent in the languages spoken by the participants which meant that there was no need to have

an interpreter during the interviews. This can be seen as an advantage because the use of interpreters may negatively influence the integrity of a study (Levin, 2006). Levin stated that the use of interpreters can compromise patient confidentiality. It is also possible that untrained interpreters can commit the five basic errors of interpretation: omission, addition, condensation, substitution and role exchange. All of these errors can compromise the exchange of information between the interviewer and the participant, as well as alter the dynamics between all parties involved by virtue of removing control of the interview from the interviewer. These issues, however, were not present in this study.

The use of vernacular languages ensured that the researcher was always in control of the direction of interview, and was able to probe where necessary (Solomon *et al*, 2012). It was also important to address participants in the language they were most comfortable with because medical jargon is not equivalently understood by health workers and patients (Levin, 2007b). A study conducted in Cape Town amongst Xhosa speaking parents of asthmatic children proved this phenomenon. It was found that often, medical terminology does not directly correlate with the common terms used by the public and vice versa (Levin, 2007b). As such, when the healthcare professional and patient do not have the same or similar command of one language, the message can frequently be misconstrued due to the nuanced meanings of different terminologies. This problem, however, was not apparent in this study because the researcher was able to effectively communicate with each of the participants in a language that both parties were fluent in. Although most of the interviews were conducted in SeSotho, IsiZulu or SeTswana, English terms such as “arthritis” and “high blood” were used by both the interviewer and participants as there was no vernacular equivalent.



### Medical record reviews

The second mode of data collection was the review of each participant's medical records, doctor's notes and prescriptions, and pharmacy refill data sheets. Copies of each document were made at the beginning of each interview, with the written consent of the participant, and later reviewed by the interviewer. The documents were used to compare the prescribed instructions to the account given by the patients, as well as the description of their illness compared with the doctors' diagnoses. Upon review of these documents, it was possible to determine areas where the patients had not been adherent to their prescribed regimen and where systemic errors had contributed to the non-adherence, such as when the pharmacists reported that pharmacy had had no stock of prescribed medications. The documents also provided insight into the perspective and professional opinions of the healthcare providers regarding the patients' condition and treatment and compensated for healthcare providers not being interviewed as part of this study as their opinions were considered by virtue of the records kept.

### Ethnographic principles

Ethnographic principles were also employed as a means of data collection, to a lesser extent than the use of the video recorded interviews. The ethnographic approach is a method, developed by anthropologists, that is gradually being adopted into medical research (Roberts, 2009; van der Geest & Finkler, 2004). The method is used in qualitative studies to describe the naturally occurring environment and human behaviour through observation (Sunderland *et al*, 2012; Roberts, 2009). It has also been shown, through these studies, that the dynamics that occur within the hospital setting are a reflection of the culture of the society being served by the hospital. Hospital ethnography has the potential to provide insight relating to the socio-economical, cultural, and linguistic context of the population (van der Geest & Finkler, 2004).

In this study, by means of a research journal, the researcher was able to document the daily proceedings of the clinic along with the behaviour of both healthcare providers and patients, giving a holistic view of the clinic culture. Although true ethnography was not implemented, some of the principles were used to collect information describing the research site. The amount of time (eight hours a week for six weeks) spent at the clinic allowed for the researcher to gain an insider's perspective of the clinic, while still being an outsider by virtue of not being part of the clinic personnel. The time was used to record informal interactions between patients and healthcare providers, and conversations held between patients. This is a phenomenon described by Thomson (2011) and found to be particularly useful in medical research when conducted by a researcher with medical knowledge, such as the researcher in this study. The use of ethnographic principles allowed for better contextualisation of the clinic environment therefore enabling the findings to be more than just a "snapshot" of one participant's experience, but rather an indication of the entire clinic experience (Lambert *et al*, 2011). A research journal was kept by the researcher in which information about the clinic context was recorded.

Ethnographic observations were recorded by the researcher throughout the day, between interviews so as to provide a detailed description of the daily clinic proceedings.

## **DATA ANALYSIS**

The video-recorded sessions were transcribed by the researcher. Where the interviews were not conducted in English, the findings were translated back into English before being transcribed. All the interjections during conversation such as the use of words like "uhm" and "uh" were transcribed to indicate where patients may have hesitated or needed to think more carefully about their answers. Non-

verbal communication was also included in the transcripts where patients used it in place of verbal responses such as when patients shook their head instead of using the word “no” to respond to a question. As it was not always possible to translate certain phrases into English, these were paraphrased. Care was taken not to alter the meaning of these phrases from the original meaning as expressed by the participants. An independent senior nurse, who was fluent in all the languages used during interviews, was given a random sample of five transcripts and the corresponding video interviews which she back-translated and verified (*Appendix C*). This process served to limit researcher bias in translation and transcription and ensure reliability of transcription as described by Temple & Young (2004).

Video-recording proved to be a valuable part of the analysis phase. This method allowed for accurate transcribing of each interview. The method made it possible to make note of all the non-verbal information such that every aspect of the interview could be recorded. This enhanced the transcription process.

Thematic analysis was the qualitative method used in this study. Smith & Firth (2011, p52) stated, “thematic analysis is an interpretive process in which data are systematically searched for patterns to provide an illuminating description of the phenomenon”. The 6 phases of thematic analysis, as described by Braun and Clarke (2006) have been used in various qualitative research studies (Silver *et al*, 2010; Penn *et al*, 2011) and were also used in this study. The use of this widely accepted method of looking for themes across a data set adds to the validity and trustworthiness of the findings generated from this study.

Because it was anticipated that the transcripts would produce bulky data, each transcript was summarised, highlighting the important issues raised within each interview (*Appendix D*). These summaries were then used to identify recurring topics and possible themes across the data set (Graneheim & Lundman, 2003). Themes were only generated once all

the transcripts had been individually analysed in order to accurately identify themes that ran across the entire data set. Existing literature on adherence and RA was also employed as a guide to develop the themes (Kumar *et al*, 2011; Schneider *et al*, 2008). Themes were created by grouping together similar issues that were raised by patients. For example, all the patients responses that related to how patients interacted with medication were grouped together to form a theme. Issues raised that had to do with systemic errors within the health system were also grouped together to create a theme, as was done with the responses that described the effect of RA on their daily lives, and how they accessed and understood information regarding RA. Each theme was thus an indication of similar matters raised by the participants that could affect their adherence levels. From the themes, the researcher then identified the areas in which recommendations could be suggested in an attempt to improve adherence behaviours.

Outliers that were found to be relevant and of value to the study were also analysed and described. In a study conducted by McPherson and Thorne (2006), the value of outliers and exceptions that do not necessarily correlate with the bulk of the data was discussed. It was found that the exception, in qualitative data, highlights a point in the research dynamic where further probing ought to be conducted so as to better explain the nuances and complexities of the research context. A discussion of outliers thus adds richness to the findings that may not have been possible in a quantitative study where the outlier may not have been significant enough to be discussed in great detail.

Patton (2004) stated that data triangulation is ideal because it strengthens a research study by incorporating a number of data collection approaches to accurately describe a particular phenomenon. The use of three methods of data collection, namely observations, record review and interviews, allowed for triangulation of findings

during the analysis phase. Triangulation thus ensured that this study was more sensitive to the nuances of the adherence phenomenon within the RA clinic setting.

## **RIGOUR**

In order to ensure the subjectivity of the findings produced from this study, elements of qualitative rigour were incorporated into the study methodology. Qualitative rigour is defined by four different principles which describe various elements of the research process where measures can be taken to ensure that the research process was exhaustive and the findings are thorough (Thomas & Magilvy, 2011).

1. Credibility.
2. Transferability.
3. Dependability.
4. Confirmability.

In this study, measures were also taken to ensure the presence of all four elements of qualitative rigour.

In order to improve the rigour of the study, the researcher kept a journal and an audit and decision trail in order to explain the rationale behind each decision taken during the process of the study. This improved the dependability and credibility of the study. A process of peer debriefing was also employed, where the supervisors reviewed the analysis of data completed by the researcher. This further minimized bias, thus, ensuring objectivity and ensuring the study's confirmability and reliability (Long & Johnson, 2000).

The credibility of a study can also be described as the truth value of the findings produced from the study. Credibility is achieved when others can understand the experiences described within the study in greater detail (Thomas & Magilvy, 2011). In this study, various methods were implemented to ensure that the findings were truthful and credible.

Three research methodologies were used in this study so as to describe the clinic text and patient experience in the greatest detail possible. The researcher went to the clinic on numerous occasions before, during and after the data collection phase to make ethnographic observations. This immersion in the clinic context allowed for a more accurate description of the clinic.

It was also desired that data saturation be reached during the data collection phase as this would make it possible to establish patterns that were apparent throughout the entire data set, and make it easier to create themes that were representative of the data. Since the data from each week was analysed before the interviews for the following week were due to be conducted, it was noted that data saturation was reached in the second last week of data collection, once 15 patients had been interviewed. However, the decision was made to interview an additional five patients to guarantee the achievement of data saturation. Once the translation and transcribing was completed, peer debriefing sessions were held with the supervisors to ensure that the researcher's analysis of the transcripts was an accurate description of the patient interviews, thus, eliminating researcher bias. Extracts from the interviews with patients are included in the findings section verbatim as that was the most truthful representation of the patients' individual circumstances. By employing all these measures, the credibility of the study was enhanced.

Transferability refers to the applicability of the methods and findings of the study to another group of participants. It is achieved by giving a detailed description of the study participants, method and the research site such that another researcher could recreate the study (Thomas & Magilvy, 2011). In this study, the ethnographic observations allowed for a detailed description of the clinic setting which included the staff, their duties and the daily routine at the clinic. The patient demographics were also described. This study can be recreated in a similar setting with a

similar demographic, thus, transferability has been enhanced.

Dependability refers to the consistency of the study. This principle can be achieved by means of a decision trail that justifies and explains all the decisions taken by the researcher throughout the research process (Thomas & Magilvy, 2011). The researcher kept an audit trail throughout the study where all decisions regarding the study were documented. The peer debriefing sessions also served as an assessment of these decisions as they allowed people other than the researcher to participate in the analysis of the data. The interview setting and the materials used during each interview were also consistent. This means that the each participant was exposed to the same interview environment and thus, environmental inconsistencies did not affect the findings of the study.

Dependability was therefore enhanced in this study.

Confirmability refers to the objectivity or neutrality of the study. It is achieved when credibility, transferability and dependability are present in a study (Thomas & Magilvy, 2011). As previously stated, a number of measures have been incorporated into this study to minimise researcher bias and ensure confirmability.

## **ETHICAL CONSIDERATIONS**

Permission to conduct the study was obtained from the CEO and Medical Advisory Committee of the hospital, as well as the head of the Rheumatology clinic (Appendix E & F). Ethical clearance was also obtained from the Human Ethics Research Committee (Medical) at the University of the Witwatersrand. (Appendix G & H)

Possible ethical problems were pre-empted and addressed as follows:

- The copies made of each prescription had the names or signatures of the relevant doctors covered or deleted so as to protect their identity.

- The patients' names were not included in the data management; a code was allocated to each patient such that their identity was not traceable by anyone other than the researcher.
- The video-recordings were stored as stipulated by the Health Professions Council of South Africa (HPCSA) (Appendix I).
- Pre-prepared drug information sheets were used together with verbal explanations to address any concerns and misconceptions expressed during the interviews by participants regarding their drug therapy (Appendix J).
- Patients were referred back to the doctors if the researcher thought that there were issues or misconceptions that could be a danger to the patient's health.

Written consent was obtained from each participant prior to their participation in the study (Appendix K). Separate consent was obtained for approval to be video-recorded (Appendix L). English was the language used on the consent forms but prior to reading it, the researcher provided a verbal translation of content to each participant in their home language. This ensured that patients who were illiterate or not fluent in English were fully aware of the facts of the study prior to their consenting.



## CHAPTER FIVE: FINDINGS

The findings revealed a wide range of factors that may influence patients' adherence levels and medication taking practices.

These issues described the complexity of the adherence phenomenon as they included organizational, social, cultural and personal factors that affected the patients' relationship with their disease and prescribed medication. There were also matters relating directly to the nature of the disease and its treatment that affected their adherence.

The findings also revealed areas where misunderstandings between patients and healthcare providers had occurred, and perhaps where effective communication as described by Tay *et al* (2011) was not achieved.

Each issue raised will be discussed using illustrative extracts from interviews with the participants which best addressed or described the factor and how it may have affected their level of adherence. The context of each statement will also be indicated where necessary so as to clarify the intended meaning.

As demonstrated in the study conducted by Solomon *et al* (2012), issues that were similar in nature, such as those in the list given above, were grouped together and categorised across the data set. From these groupings categories were formed and used to create four general themes as illustrated in Table 6. The four themes were created because they covered factors identified in most of the interviews and encompassed the categories well.

This section will discuss each theme and its contributing categories, as they appear in Table 6, in terms of how the issue may enhance or hamper adherence rates in patients with RA. The themes were not listed according to priority or salience because elements of each theme were present in each interview, thus, each theme is equally important in describing the data.

*Table 6: Overview of themes and categories identified in the data*

<b>THEMES</b>	<b>CATEGORIES</b>
Effect of RA on living experiences	<ul style="list-style-type: none"> <li>• Effect on physical abilities</li> <li>• Emotional aspects: denial, shame, fear, anger</li> <li>• The role of support systems</li> </ul>
Interactions with medication	<ul style="list-style-type: none"> <li>• Co-morbidities</li> <li>• Access to medication</li> <li>• Self-medication</li> <li>• Side effects of RA treatment</li> <li>• Generic substitution</li> <li>• Burden of taking medication</li> </ul>
Level of understanding and access to information	<ul style="list-style-type: none"> <li>• Influence of cultural and social beliefs</li> <li>• Communication with healthcare providers</li> <li>• Use of technology</li> <li>• Language barriers</li> </ul>
Experience of healthcare services	<ul style="list-style-type: none"> <li>• Local healthcare experience</li> <li>• Out-patient RA clinic experience</li> <li>• Pharmacy experience</li> </ul>

## **EFFECTS OF RA ON LIVING EXPERIENCES**

This theme refers to the ways in which having RA has altered the day-to-day living experiences of patients and how those experiences have affected their adherence to prescribed medication. The ability to move and the sense of independence that comes with being able to perform daily tasks are factors that can easily be taken for granted by people who are not facing a disease like RA. In RA patients, however, as described by Schneider *et al* (2008), these issues can have a significant impact on the life of someone affected by RA. Participants expressed not only the physically debilitating effects of RA, but also the emotional toll that the disease can have on one's life (Picchianti-Diamanti *et al.* 2010). Because RA can negatively affect the ability to perform vocational, avocational and self-care activities, it can greatly influence the emotional well-being of affected patients which may subsequently affect their adherence levels (Clements, 2012; Stenstrom & Minor, 2003; Hochberg *et al*, 1992).

All of these effects advocate for the patients to have a strong support system on which they can rely to assist them through the difficulties associated with RA. Holtzman *et al* (2004) postulated that although there is no clear mechanism that explains how a good support system affects one's health, good social support can help someone to understand a situation better and thus adapt their behavioural responses appropriately. Taking that into consideration, a strong support system can assist an RA patient to better understand their disease and thus influence them to adhere to prescribed medication.

This theme was divided into three categories:

1. Effect on physical abilities.
2. Emotional aspects and.
3. Support system.

### Effect on physical abilities

RA can, as previously stated, cause extreme disfigurement of the joints, which greatly restricts motion. This often results in discomfort and the inability to perform daily tasks. Compromised mobility is the one factor that was noted by all the participants. Each one explained that the pain and difficulty in carrying out everyday activities often led to them taking their medication in an effort to improve their living experience. Here, two participants describe the impact that reduced physical activity has had on their lives:

**P8:** *You can no longer do things the same way you used to. You work very cautiously so that you don't hurt yourself...Even bathing, that time when it was still really bad, I couldn't wash my face. I would wait for the day when the pains weren't as intense and bath then.*

**P11:** *To get out of bed would probably take me longer than 15-20 minutes 'cause I need to have a strategy of getting out of the bed, actually. I found that I stopped sleeping on the bed 'cause it was harder to get out of bed then it was actually easier to sleep on the couch.*

Since RA cannot be cured, the introduction of medication does not completely reverse what damage has already occurred. It does, however, slow disease progression and reduce discomfort. This can then make it easier for patients to perform daily tasks. The knowledge of their past physical condition, as opposed to their condition once prescribed medication was initiated, often served as motivation for participants to take their medication.

**P13:** *I know where I used to be [before I received proper treatment] and what helped me.*

Even though RA is not a welcome addition to patients' lives, the medication can provide relief from the negative living experiences that RA can cause. The contrast between life without medication and life

once medication was prescribed appeared to have a positive influence on patient adherence levels.

### Emotional aspects

A number of the participants expressed feelings of denial or shame that could promote reluctance to adhere to the medication as prescribed. Often, the denial was sparked by participants who believed that they were too young to have a disease like RA, a disease generally associated with the elderly. Failure to believe in the diagnosis often led to a lack of confidence in the medication, which might have hindered adherence. In a study conducted by Murray *et al* (2009) on HIV positive Zambian women, it was found that denial is often a sign of the patient's lack of familiarity with the implications of having a chronic disease. They found that the participants could not accept the necessity for chronic medication and the profound lifestyle changes that were necessary in order to accommodate the treatment regimen into their daily lives. It can be argued that RA patients could also go through a stage of denial due to the inability to accept the implications of having RA and taking the necessary treatment. In the same study, it was also found that as a result of the cultural framework where most forms of medicines are considered curative, accepting that one has to take medication on a permanent basis made it more difficult to accept prescribed treatment, which may also be relevant in the case of RA.

Aldebot and Weisman de Mamani (2009) found that schizophrenic patients who struggle to accept the chronic nature of their disease, for reasons such as ignoring the magnitude of their symptoms, and thus the necessity of lifelong medication, are more likely to be less adherent to prescribed medication.

Although the nature of RA as a disease cannot be compared to that of HIV and schizophrenia, it is possible that patients can go through similar

emotions and thought processes as they begin to accept their diagnosis. Here, two participants express their denial upon being diagnosed with RA:

**P4:** *I didn't believe it... I even disputed it with the doctor.*

**P5:** *[it was] denial. You look at your age and you're so young and you have a husband and all these things, and for you, having arthritis is something that you think you're over the wall, you're finished.*

One participant reported that she sometimes grew angry at her medication which often led to reduced levels of adherence. She was, however, an outlier as other participants expressed that they sometimes grew angry about their general condition, but the anger was never explicitly directed at the medication. The anger felt by P14 led her to avoid taking her medication, thus, her adherence levels were compromised. P14's behaviour is similar to the phenomenon described by Leombruni *et al* (2009) who stated that anger towards both a disease and its treatment can increase reluctance to take prescribed medication. This would then negatively affect the patient's adherence levels. Here, P14 describes how she felt angry at her medication and how she would deliberately not take her medication as a result of her emotions:

**P14:** *I get angry at them (the pills)...even when I feel pain, I sit with that pain. And it will hurt but I will ignore it and leave it that way. I tell myself that I don't want [the pills].*

It was implied by one other participant that her self esteem and general opinion of herself had deteriorated as a result of her diagnosis and having to rely so heavily on medication. Such negative mindsets, as a result of the medication, can reduce the willingness of patients to adhere to medication.

In an autoethnographic study of his experience with prostate cancer, Karnilowicz (2011) describes the complexity of psychological ownership of a chronic illness. He describes psychological ownership as the process where an individual is able to fuse their identity with the respective disease; a difficult process to complete because psychological ownership also implies that the patient assumes responsibility and control of their condition. In a patient with RA, control of the disease could be linked to medication taking principles because if an RA patient adheres to prescribed medication, they can control the disease progression and thus assume responsibility for their health. Thus achieving control of their disease can be used as a strategy to motivate patients to adhere to prescribed medication.

“Self-identity is often the subject of greatest change when confronted with an epiphanic experience” (Karnilowicz, 2011, p280). Here, participant P18 describes how, even though she had been taking her medication and was experiencing relief of her symptoms, she was still struggling with her self esteem and how she identified herself:

**P18:** *I feel small. I'm no longer brave. Everything about me has gone down...my life, in general, has not been improved but the pains have been reduced.*

Fear appeared to be the emotion that promoted adherence the most. Participants explained that they adhered to their medication because they were afraid of experiencing the pain associated with RA. They were also afraid of the consequences of allowing the disease to progress as a result of poor adherence. Here, two participants express their fear of the pain and deformities that can result from RA:

**P11:** *The pain I felt, I never wanna feel that kind of pain and, on a serious note, I don't wanna wish it on somebody.*

**P12:** *If you don't take your treatment properly, you could become deformed. Yes, it bends your hands, it bends your feet, it bends your knees. You could find yourself deformed if you aren't careful.*

P11 and P12 were participants who, according to their verbal accounts and the doctors and pharmacy records, had been adhering to prescribed RA treatment.

This category shows some of the emotions that are associated with being diagnosed with RA and having to live with the reality of the disease and its treatment. Through the accounts of these patients, it can be seen that emotional and psychological support by healthcare providers could contribute toward patients having a better understanding of the disease and subsequently adhering to prescribed treatment. This notion is supported by Karnilowicz (2011) who echoed the importance of healthcare providers helping patients to integrate new health behaviours into their lives.

### Support System

Having a strong support system is an important part of chronic therapy. Having people other than the hospital staff who can encourage patients to adhere to therapy can contribute greatly towards improving adherence and disease outcomes (Holtzman, 2004; Evers, 2003). Family members who express concern and compassion towards patients was noted as one of the reasons participants continued to take their medication as prescribed. Here, a participant expresses how her husband insists on her taking her medication:

**P6:** *I have a husband who loves pills. He is so strict about me drinking them.*



The majority of participants, however, mentioned that they had nobody who took an active role in supporting them with taking their medication. They had to find ways of reminding themselves. Adherence appeared not to be hindered by this as most patients expressed that they had developed a routine which made it easier for them to adhere to their prescribed regimen.

The problem with the lack of a support system manifested when participants were having particularly bad days with regards to the pain. On such days, they required the assistance of family members. A number of participants felt that they became a nuisance on family members and as a result, could not ask for help, and this reportedly negatively affected their adherence levels.

On days where the participants stayed in bed and were unable to move because of severe pain, they begin to resemble the palliative care patients studied by Overturf Johnson *et al* (2007). In this study it was stated that patients with chronic disease, much like terminally ill patients, have a fear of being a burden on their family members. As a result, these patients may refrain from asking for help at the expense of their health.

Here, participant P16 describes the moments where she had been in too much pain to help herself and had to ask her children for help:

**P16:** *You suffer to the point where you irritate people. Even the children, when you keep calling out [for help] are like “oh gosh, my mother”. But you can also see that they have had enough.*

This category indicates circumstances where adherence may be affected because of a patient's home environment. In the case of P6, she had a supportive husband who insisted that she take her medication. This type of support can increase adherence levels. In the case of P16, she felt however that she would at times become a burden to her children. The

fear of being a burden, as explained by Overturf Johnson *et al* (2007) could, at times, have prevented her from requesting the assistance of her children with regards to accessing her medication. In this way, her adherence levels could have been negatively affected. These findings indicate that support networks are complex and have the potential to be inhibitory or supportive to patients with chronic conditions. Healthcare providers could assist patients in this regard by forming networks that would potentiate improved medication adherence.

### **INTERACTIONS WITH MEDICATION**

Medication is an integral part of life with RA because it is usually initiated at the point of diagnosis. This means that RA patients have to develop some sort of relationship with their medication or establish a daily routine that encompasses their medication. Thus, medication is almost unavoidable in the life of a patient who embarks on a treatment journey for their RA.

This theme refers to the manner in which participants relate to their prescribed RA medication, as well as any other forms of medication that they may have been taking. It is important to consider the use of other medications, conventional or complementary, as the various compounds may interact. These interactions may have effects similar to those that would be present if the patient was non-adherent.

There were six categories in this theme:

1. Co-morbidities.
2. Access to medication.
3. Self-medication.
4. Side-effects.
5. Generic substitution.
6. Burden of taking daily medication.

### Co-morbidities

Many of the participants suffered from other chronic diseases such as Hypertension and Diabetes Mellitus (*Table 5*) and were receiving treatment for these conditions, along with the RA medication. Often, this resulted in confusion and participants not adhering to all their medication as it had been prescribed because they did not always relate their drugs to a specific symptom of disease. It seemed that patients were more inclined to adhere to the RA medication than to that which was prescribed for their other conditions. This could be due to the fact that the clinic is primarily an RA clinic even though patients have all their other medication prescribed by the rheumatologists. As evidenced during observations at the clinic, the interactions and communication within the clinic, such as the available drug information leaflets, focused on the importance of treating RA and the patients' mindsets seem to have been influenced as such. This was displayed by participant P7 who was the participant who appeared to have the most knowledge about her RA medication and had been proactive in her approach to her RA by attending various educational conferences. Her medical records indicated that she had uncontrolled hypertension but she seemed not to be as concerned about the threats this posed, such as increased chances of stroke or myocardial infarction, as she was about pain and disability that may result from uncontrolled RA:

**P7:** *In all honesty, I'm not as concerned about the high blood ones. I take them because they're my pills but it's not something that's on my mind. What's on my mind is this (RA).*

Participant P15 had been diagnosed with hypertension as well, and had been prescribed medication for the condition. She also expressed that she would at times experiment and not take the antihypertensives

because she wanted to see how her body would react or if she could reduce the medication related adverse effects:

**P15:** *I skip days with the high blood ones. I don't want to lie...I want to feel if the dizziness that I get is there when I don't take it.*

This category speaks to how the patients appear to prioritise their respective diseases and assign varied levels of importance to each condition. The patients seem to have prioritised the co-morbid conditions as inferior to RA (Pound *et al*, 2005; Townsend *et al*, 2003). This may have been because the pain and other symptoms of RA may have had a more pronounced impact on their daily lives than the effects of hypertension, which is often asymptomatic, would have. In the study by Townsend *et al* (2003) a phenomenon was discussed that involves patients adopting both regular and flexible regimens to the diseases affecting them. Patients would adhere strictly to the regular regimen of the disease to which they had assigned the highest priority and were less likely to adhere to prescribed medication for diseases that they felt were of lesser importance. P7 and P15 were two of the patients who appeared to be exhibiting this phenomenon.

This category sheds light on the necessity for healthcare providers not to just treat the disease, but also to treat and counsel the patient as whole. This is especially true in patients who have to deal with the complexities of polypharmacy and multiple chronic conditions (Townsend *et al*, 2003). The prioritisation of chronic conditions can affect adherence. In this case both P7 and P15 were adhering to the prescribed RA medication but not adhering to their other prescribed medication which can still jeopardise their overall health status.

#### Access to medication

The majority of conventional medicines that are prescribed for RA are S4 drugs (Gibbon, 2008). As indicated in Table 4, section 22 (a) (iii-v) of the Pharmacy Act, these drugs may only be purchased upon the

furnishing of a valid prescription from a doctor. Some participants, however, expressed that they could get various scheduled drugs, illegally, from private pharmacies, while others complained about certain drugs being out of stock at the hospital pharmacy where they collected their medication.

In both instances, adherence was, as described by participants, compromised. As previously explained, taking medication which has not been prescribed or not taking medication that had been prescribed can disadvantage patients as it may alter the drug concentration levels required to achieve clinical outcomes. In each case, circumstances encourage patients to take medication in a manner that contradicts the prescribed dosage instructions.

Here, participant P14 explains how she acquired prednisone without a prescription:

**Interviewer:** *How do you buy [prednisone] without a prescription?*

**P14:** *There are [pharmacists] that will sell them to you.*

This patient had once been prescribed prednisone by the rheumatologists but the drug was later removed from her regimen. She went on to explain that she had taken it upon herself to purchase the drug at a private pharmacy because she felt that it was the drug that best relieved her pain. This belief was echoed by the RA patients in the study by Kumar *et al* (2011, p840) who believed that steroids were “magic medicines” because of the rapid pain relief they brought about.

Another participant, P20, described her experience of being unable to access methotrexate:

**P20:** *And then for these 2 months, I didn't get methotrexate. Ya, and then my health wasn't very good. Very bad...They didn't have it at the chemist. And I thought of going to the pharmacy to buy but I didn't know*

*I need to go with a script and then they will help you. But it was bad these 2 months.*

A few participants also indicated that they purchased over-the-counter analgesics and anti-inflammatory agents. Although this was not illegal, the addition of such drugs to the prescribed regimen can lead to drug-drug interactions. These interactions can exacerbate the GIT side-effects experienced with RA drugs such as methotrexate (*Table 1*). The OTC drugs can also inhibit the renal clearance of methotrexate, thus increasing the risk of toxicity and jeopardising the patient's health (Gibbon, 2008).

Here, participant P2 spoke about the analgesics that she purchases at her local pharmacy:

**P2:** *Oh, I forgot to tell you about the green pills, Pynstop. That's the one I ask for at the chemist.*

Pynstop is an analgesic product that contains paracetamol, codeine phosphate, caffeine and doxylamine succinate (Gibbon, 2008). This combination of drugs is associated with side effects such as gastrointestinal disturbances, and needs to be used with caution in patients who may have compromised hepatic and renal functioning. Prescribed DMARD therapy also carries a similar side effect profile to Pynstop. This means that although the use of Pynstop does not directly affect the prescribed medication, it can exacerbate the side effects and thus further compromise the health of the patient.

The purchasing of over the counter analgesics was also expressed by a participant who was not yet on DMARD therapy. She had been newly diagnosed and was only on NSAID therapy to treat her RA. She explains how she sometimes altered her regimen:

**Interviewer:** *Are there times when you take two [naproxen] instead of one, because the pain is that intense?*

**P1:** *No, I've never taken such chances. Instead, I try to find a Panado and I take the Panado because I'm scared of taking two [naproxen tablets] because maybe it's wrong...I just take a Panado when the pain gets too bad.*

It became apparent from comments such as this, that because S0, S1 and S2 drugs are so easily accessible, patients may not view them as medication. They seem not to consider these drugs as substances which are potentially dangerous, especially for people who are already taking other forms of chronic medication. P1 displays this best because she explained that she was afraid to tamper with her prescribed medication as it may be bad for her health, but she found it acceptable to augment her therapy with paracetamol, a commonly used, easily accessible and presumably safe analgesic.

Eickhoff *et al* (2012) observed that the wide-spread use and increasing accessibility of over the counter medication has led to the underestimation of the risks involved in their usage. This may be the reason why patients often fail to report using them to their healthcare providers. In the study conducted by Eickhoff *et al* (2012), it was found that drug related problems arose from almost one in five interactions between pharmacists and patients who were self-medicating. The reason for this, they found, was that pharmacists generally do not have access to patients' files at the point of an OTC purchase so it was difficult for the pharmacist to prevent the drug related problems.

Paracetamol can be sold on the open shelves of any pharmacy or grocery store. It can be argued that because paracetamol may seem to patients as though it is not being subjected to the strict laws that govern the access to other medications, it is a less dangerous drug and need not be approached with the same caution as other drugs. The danger, however, is that Paracetamol, like all other drugs, can have fatal effects if not used cautiously (Platt-Lopez, 2009; Cohen, 2007). Here, the

findings indicate that perhaps the accessibility of lower scheduled drugs can be misinterpreted by patients, who then believe that the drug is not necessarily a potentially harmful substance.

It may be that in the case of P2 and P1, the particular pharmacists did ask the necessary questions about other medicines that they may have been taking. It is also possible that the patients did not disclose the information to the pharmacists either deliberately or because they were unaware of the importance of notifying the pharmacist about other medications that they were taking.

This category shows the effect that uncontrolled access to medication can have on the adherence levels of patients. It also shows that sometimes the patients are not well enough informed about what to do when they have trouble accessing essential drugs and that they need more counselling about the possible dangers associated with drug interactions.

### Self Medication

It also became apparent that some of the participants used their prescribed medication along with other complementary medication, such as traditional, herbal and homeopathic remedies, which was freely available in their communities. These remedies were said to come in the form of tonics or teas which patients drink.

Self medicating involves the use of non-prescription drugs, often without consultation with a medical practitioner or under their supervision (Eickhoff *et al*, 2012). The same study reports that the tendency of patients to self-medicate has increased markedly over the last decade due to the high cost of prescription medication, and because the practice of self-medicating increases the empowerment of patients. Self-medicating helps patients to feel like they are contributing towards the improvement of their health.



Here, two participants talk about the complementary medication that they use to supplement their prescribed medication:

**P7:** *I drink Forever Living [tonic]...People sell it. There are representatives who sell it. I drink the one for arthritis, the white one. There's also a brown one and a maroon one...I drink 3 [bottle lids] full in the morning.*

**P8:** *I drink Lavidia Teas...There are people who sell them. So they advertise then invite neighbours over and then make green tea and you drink it while they explain and chat to you.*

In both these cases, the patients believed that the complementary medication had had a positive effect on their RA. Unfortunately, neither participant had brought the products with them to the clinic so the contents of the products could not be determined during the interview. It was later discovered from the product website, however, that Forever Living is a product that contains Aloe vera extracts, omega oils and various other natural ingredients (Peto, 2012). The products and claims made on the website had not been approved by the Food and Drug Administration (FDA), and the items were “not to diagnose, treat, cure, or prevent any disease”, even though they were being marketed specifically to RA patients. Although the MCC was not mentioned on the website, the council generally follows the regulations set by the FDA. Thus, it can be assumed that the product did not have MCC approval either. The danger in using complementary medication, such as those mentioned by the participants, lies in the poor regulation of the compounds, the effects of which may alter the efficacy of the prescribed conventional medication (Kale, 1995).

In one instance, a participant took additional conventional medication from a family member who presumably had medical knowledge because they worked in a hospital. This could have been as dangerous as using complementary medicines in terms of possible drug interactions.

**P4:** *I once took medication that I was told was for bones, given to me by my mother. She got them from my cousin who works at a hospital.*

P4 also reported that after taking the medicine that she had been given by her family member she felt sick and believed it had given her an ulcer. She could not remember the name of the product but it appears that the product may have potentiated the GIT effects of her prescribed RA treatment and could have compromised her health had she continued to take this drug.

In all these instances, the patients' desperation or desire for improved health, or perhaps for a cure, could have made them vulnerable to possible charlatans who provided various forms of medication that in fact had the potential to negatively affect their health.

The use of topical therapies was noted by one participant. She explained that although she was comfortable with topical therapies, she thought it wrong to take complementary oral preparations. This is another example of how patients exercise their agency by making decisions regarding the perceived risks associated with certain preparations and dosage forms.

**P5:** *I use the mustard and garlic oil for rubbing. Just for rubbing. I don't drink things.*

Some participants, however, expressed concern about using medication that had not been prescribed. These participants believed it inappropriate to self-medicate. They believed that the best decision to make was to adhere strictly to the instructions of the doctors at the RA clinic. It seemed that their concerns about the doctors' reaction to their use of complementary treatments were enough to deter them from experimenting with such remedies. Participant P12 implied that she would be too afraid to tell her doctor, perhaps due to the fear of possible repercussions, if she decided to take complementary

medication and then the medication caused negative side effects. And because of that, she chose not to experiment with complementary medication.

**P12:** *I'm afraid of the after effects because if they have after effects, who will I consult?*

This category reveals how vulnerable patients can be to charlatans. It also shows how important it is for them to feel empowered and be involved in some of the decision making regarding their treatment. This may help patients have a better understanding of why they have been prescribed certain drugs, and possibly encourage them to communicate with their healthcare providers to enquire about the complementary medications that they may encounter.

Self medicating does not necessarily mean that patients are not taking their medication as prescribed, but it does mean that there is a potential for the additional drugs to interfere with the functioning of the prescribed therapy and possibly jeopardise the patient's health.

### Side Effects

RA can cause great physical distress, but so too can the prescribed medications as described in Table 1. Various unpleasant consequences can result from the use of medication and experiencing side effects can also hamper adherence (DiBonaventura *et al*, 2012; Kumar *et al*, 2011).

Some patients decided to either stop taking a particular drug or to change the dosage for the particular drug which they blamed for causing the side effect. It was also common for participants to attempt to treat themselves for the side effects, thus, leading to incorrect use of their medication.

**P2:** *These pills (calciferol and prednisone), when you take both, you feel it in your eyes...They water and become itchy so I scratch them. They turn red and close up. Then I have to wait 2-3 days to regain my sight.*

**Interviewer:** *So when it happens and they water, do you stop [taking the pills]?*

**P2:** *No, because they help with my pains. I can't stop taking them...When my eyes act up, I just alternate them, one week these (calciferol) then these (prednisone) the next.*

**P15:** *At times, when I get those hot flushes, I think it's cholesterol. Then I take 2 [simvastatin tablets] and overdose so I can sleep.*

In both cases, the incorrect decision was taken by the patient with regards to treating their respective side effects. Pharmacologically, calciferol and prednisone should have no effect on one's eyes, and simvastatin should not be used to treat hot flushes or to induce sleep. These two examples suggest that effective communication may not have occurred regarding the actual side effects and uses of the mentioned drugs.

One participant explained that she deliberately did not take her medication properly because she was aware of possible side effects as a result of observing other patients, and because the drug in question came with a referral letter to attend the eye clinic:

**P18:** *Oh chloroquine. You know, let me tell you the truth, before God, I don't take it because it damages your eyes...I don't take it, I'm being honest with you...I don't take it at all but they give it to me.*

**Interviewer:** *How did you hear that it damages your eyes? Did someone else tell you?*

**P18:** *No, when they prescribe it, they refer you to St Johns (eye clinic)...the referral letter says it's chloroquine...so I noticed then that it means they will damage your eyes.*

Participant P18 demonstrates how astute patients in this context appear to be. She weighed out the perceived risks of taking chloroquine and made a conscious decision not to adhere to her prescribed regimen. She explained that she collected her chloroquine monthly so that her pharmacy records would indicate that she received all the prescribed treatment, but she did not use the medication. Her therapy would thus be compromised because she was not adhering to prescribed therapy which put her at greater risk of her RA progressing more rapidly.

This category illustrates how a lack of understanding about the functioning of prescribed medicines, along with actual or perceived side effects can cause patients not to adhere to their prescriptions. It also indicates that patients are not passive consumers; in many cases, patients may decide to take control of their own therapy if they feel that the medication could be causing greater damage to their overall wellbeing. Healthcare providers need to be aware of such behaviours so that they may be able to provide appropriate information and monitor each individual situation.

### Generic Substitution

The Medicines Act (s1 (iii)) defines interchangeable multi-source medicines or generic medicines as “medicines that contain the same active substances which are identical in strength or concentration, dosage form and route of administration and meet the same or comparable standards, which comply with the requirements for therapeutic equivalence as prescribed”. Such products can be substituted or dispensed interchangeably to patients.

Although generic drugs are essentially the same, they have different trade names and this can be confusing to patients and may negatively impact on their ability to adhere to prescribed medicines (Hakonsen & Toverud, 2011; Hakonsen *et al*, 2009). These studies also found that confusion came from patients' uncertainty about the quality of generic drugs since they were often cheaper than the original products and were perceived as possible counterfeits.

From the accounts of the participants interviewed in this study, the concept of generic substitution seemed not to have been adequately explained to them by the dispensing pharmacist. As a result, when they received products that they were not familiar with, adherence was often negatively affected.

Here, P8 explains how she did not take new products until her next visit to the RA clinic, at least a month later:

**P8:** *Me, when I don't understand what something is for, I come back with them. Then I ask the Dr what they're for during my [next consultation]...They (at the pharmacy) shove your things at you. So then I put them aside. If I remember, when I come back to the clinic or to collect my repeat, I bring them with to ask what they're for.*

This patient was very assertive and realised that she was entitled to know what medication she was taking. Although it was a positive thing that she felt comfortable enough to approach the clinic staff about products she was uncertain of, she would have still gone a month without taking her treatment exactly as it was prescribed. Ideally, she should have been informed about the generic product at the pharmacy when she collected her treatment.

In another interview, participant P14 described her experience of various drugs having been dispensed to her as alternatives for each other. The drugs she mentioned, however, were not generics and

should not have been substituted for each other. It may be that the pharmacy had no available stock of the prescribed drug or the appropriate generics so they dispensed medication that would still yield similar clinical results as that which was prescribed. In this instance, through no fault of her own, the participant had compromised her adherence because her drug regimen was being erroneously altered by the dispensing pharmacists.

**P14:** *diclofenac works like Voltaren...Sometimes when you don't have diclofenac, then there's naproxen...Sometimes at the pharmacy they don't give them all to you...Sometimes it's naproxen or prednisone. Then they don't give you diclofenac.*

Voltaren is the trade name for a diclofenac containing product. That means Voltaren may be substituted for another product, of the same dosage form, containing the same amount of diclofenac. Naproxen is an NSAID like diclofenac but the products cannot be substituted for one another, neither can they be substituted for prednisone which is a glucocorticosteroid drug. Participant P14 seemed to recognise the need for generic substitution but her explanation of her pharmacy experience demonstrated that she may not have known the conditions under which drugs may be substituted.

The literature shows that generic substitution can pose a challenge to the achievement of medication adherence (Hakonsen & Toverud, 2011; Hakonsen *et al*, 2009; Watermeyer, 2008). This could result from patients not being able to identify the generic as part of their prescribed regimen because many generics do not look the same as the original drugs. It may also be problematic if patients are not helped to understand that the contents of a generic drug are the same as those of the original drug. It has also been noted that much of the challenge may be overcome if patients are adequately informed about generic substitution. This is true for both of the situations described above.

This category highlights the challenges that generic substitution can pose when it comes to achieving medication adherence. The need for more effective communication between patients and healthcare providers has also been shown. This is especially true for the interactions between patients and dispensing pharmacists, when patients receive their medication. Better communication could result in improved adherence for patients who are confused about generic substitution.

#### Burden of taking daily medication

In a study conducted with patients with chronic heart failure, Gallacher *et al* (2011) described treatment burden as a phenomenon distinct from disease burden. They cited issues such as poor communication with healthcare providers, polypharmacy, enacting lifestyle changes and the frequent visits to hospitals or pharmacies as factors that increased treatment burden. Viewing treatment in a negative light could increase reluctance to adhere to prescribed medication.

Many of the participants in this study expressed that they grew weary of taking multiple medication on a daily basis. As a result, they took 'breaks' from their medication; days when they were just not prepared to take the medication regardless of the pain. This action may have hampered adherence. Since RA is not an infectious disease like HIV or Tuberculosis, missing a few doses may not result in treatment failure or resistance against prescribed drug therapy (Dahab *et al*, 2008, McInerney *et al*, 2007). However, if the act becomes a habit, it may lead to increased disease progression and disability for the patient. As a result, upon examination by a doctor, it may appear that the treatment was ineffective and needs to be increased or appropriately altered.

Here, two participants describe scenarios where they deliberately chose not to take their medication:



**P6:** *Sometimes you just want a break from them. You don't want any pills that day...You just tell yourself that you're not taking them that day and you'll just see what happens.*

**P13:** *Sometimes, though, I stop. Maybe for a day, I stop just to see how I will cope...I just want to know how my body would feel...Then it hurts and I sit. At night I think about taking them but I decide against it, just for a day.*

Unlike some RA patients in the study conducted by Kumar *et al* (2011) who did not believe that having RA meant that they had to take life-long daily medication, P6 and P13 stated that they understood this fact. They had still decided not to adhere to prescribed treatment on certain days. It was not completely clear what motivated the decision not to adhere to treatment.

One participant was concerned about the burden the medication placed on her body. She worried that even though the medication helped to alleviate the symptoms of RA, it was also causing harm to her body. Such opinions indicate the need for increased reassurance from healthcare providers regarding the effectiveness of medication as well as an explanation of potential side effects. Patients need to be encouraged to adhere to medication and reassured that, despite the possible side effects which may at times cause them to feel unwell; their overall health related quality of life will be improved.

**P7:** *It's helped but at the same time I worry. I'm worried about what it's doing to me. I don't want to lie, it bothers me. I'm always on them. They have become my life. I ask myself because our bodies were made to fight for themselves. So now, what's going on inside mine?*

Participant P7's views resonated with other RA patients who stated that even though they understood the necessity of DMARD therapy, they had concerns about the long-term effects of medication on their bodies

and the reality of being dependent on the medication to help them retain good quality of life (Kumar *et al*, 2011).

This category speaks to the personal challenges that patients have with their medication. It describes the emotional struggles that they may face as a result of having to alter their lifestyles to incorporate daily medication. These challenges call for increased support and reassurance from healthcare providers to patients about the importance of adherence.

### **LEVEL OF UNDERSTANDING AND ACCESS TO INFORMATION**

As previously discussed, effective communication is an essential part of the interactions that take place between patients and healthcare providers (Tay *et al*, 2011; Haskard-Zolnierek & DiMatteo, 2009; Street, 2002). The achievement of effective communication would lead to patients having a greater understanding about RA and thus enabling them to make better informed decisions regarding their medication taking behaviours. Effective communication also enables the healthcare provider to have an improved understanding of the patient's experiences and perspectives (Salt *et al*, 2012; Hemsley *et al*, 2011).

This theme refers to the transfer of knowledge between patients and healthcare providers, and the subsequent level of understanding present in these interactions. The patient interviews revealed areas where effective communication had not been achieved and where patients did not have full understanding of issues regarding both RA as a condition and the prescribed treatment. This misunderstanding of various concepts regarding their health could have an effect on their adherence levels (Tay *et al*, 2011).

There are four categories:

1. Influence of cultural beliefs.

2. Communication with healthcare providers.
3. Use of technology.
4. Language barriers.

#### *Influence of cultural and social beliefs*

The general demographic of patients at the clinic consists mainly of people of African origin. Culturally, these patients' perceptions of health may have been exposed to and possibly influenced by various cultural beliefs. Some of these beliefs may have influenced the participants' understanding of RA and led to misconceptions regarding the condition and the manner in which it is treated which did not align with a biomedical viewpoint (Wasti *et al*, 2009). Wasti *et al* (2009) explored the effect of Nepalese culture on adherence to antiretroviral therapy. They found that culture can influence the attitudes and views of people regarding their disease and its treatment, therefore, culture could affect the behavioural approaches of patients regarding adherence to conventional treatment strategies. It has also been found that some patients believe their chronic illnesses to be as a result of curses, bad karma or a form of punishment from God (Kumar *et al*, 2011; Wasti *et al*, 2009).

One participant, when asked about the cause of her illness, relayed a story about being visited by a snake. This snake is known to bring bad luck and curses to the person it appears to, even though the snake itself never harms the individual.

**P16:** *That snake! I was a child, so we slept on the floor. When I woke up and was folding the blankets, it was curled up as I was lifting the sponge/mattress. I, obviously, hadn't seen it because I was quiet and folding the blankets. When I wanted to call out to my brothers to show them what I saw as I lifted the sponge, [my throat] was this big (swollen)! When I tried to speak, I couldn't. There was just a nasal sound.*

This patient believed that the snake had appeared to her as a sign that she would be cursed with bad health. Along with causing the RA she also explained that she and many of her family members had been diagnosed with cancer and she believed that it all began because of her encounter with the snake.

Some of the participants, when asked about the cause of RA, related 'old wives' tales' and traditional views about the disease. They believed that RA had been caused by domestic chores that involved submerging their hands in water for prolonged periods of time, such as while doing laundry and scrubbing floors. The weather, cold temperatures in particular, was also expressed as a cause of RA. Although these beliefs did not directly influence adherence, these responses indicate that more counselling was needed in order to correctly explain the aetiology of RA to patients.

**P15:** *It feels like I have ice inside [my bones]*

**P3:** *My bones are filled with cold.*

**P1:** *The way I see it, I think because I spent many years working as a domestic worker, doing laundry and ironing. Maybe that's when it started and I ignored it. I also think using water often, and electricity with ironing, caused it.*

These participants' accounts also showed how patients use metaphors to describe their symptoms. Semino (2010) described how patients suffering from chronic pain often use metaphors to try and describe the severity of their pain when they communicate with healthcare providers. Samford Fair (2003) found that there were disparities in the manner in which healthcare providers and RA patients explained matters relating to the disease, and that finding ways to address the disparities and create mutual understanding could improve clinical outcomes.

“Ramatiki” was a term brought up by a few of the participants. The term is derived from the word “rheumatic” and has been used in indigenous cultures such as SeSotho, SeTswana and IsiZulu to describe a disease that damages bones.

Here, a participant responds to a question about the cause of her RA:

**P13:** *That’s a tough question because before, when such things affected our mothers, they said it was Ramatiki. They didn’t know that it was arthritis...they thought it was caused by water because they did a lot of washing as domestic workers...They thought it was water and cold.*

During an interview with one of the rheumatologists at the clinic, she explained that because the true cause of RA is yet to be known by the doctors, and that because “it’s [still] a mystical problem why your joints will suddenly swell up and erode”, there is room left for patients to question and speculate for themselves. As a result, the myths, such as curses and domestic chores causing RA, had yet to be effectively dispelled. She acknowledged that the doctors needed to do more in terms of counselling patients and finding out what their beliefs were. The senior sister expressed that she was beginning to question and discuss these myths at the clinic school so as to enlighten patients.

This category serves to enlighten healthcare providers about the kinds of beliefs that patients have about their disease states. These beliefs, as can be seen in the above examples, can sometimes be very different from the biomedical viewpoint and thus lead to disparities in understanding as explained by Samford Fair (2003). Myths and cultural beliefs may not directly affect adherence to prescribed treatment, but perhaps they are areas that require more attention and investigation from healthcare providers in an attempt to help patients to have an improved understanding of the biomedical perspective, and to ensure that healthcare providers have a culturally sensitive approach when addressing patients (Barksdale, 2009).

### Communication with healthcare providers

As has been discussed, effective communication has the potential to increase adherence levels by creating better understanding of the disease and prescribed treatment regimens (Tay *et al*, 2011; Makaryus & Friedman, 2005). Participants who expressed that they found it easy to approach the clinic staff for clarification seemed to have better levels of adherence, based on the comparison between their verbal accounts and their clinic and pharmacy records. It seemed that these patients had managed to forge trusting collaborative relationships with the clinic staff, thus, their ability to communicate effectively was improved.

Here, one such patient described a conversation with one of the rheumatologists who walked past her while she was waiting to enter the interview room:

**P20:** *I remembered now to ask [the Dr] but it was just one of the things. She explained it's part of the arthritis...Most of the time, [they] are very helpful. Really they are helpful.*

This patient explained that she always felt able to approach the doctors and enquire about RA and her treatment.

Some participants, however, expressed that they found it difficult to seek advice from the doctors because the doctors were too busy.

One participant admitted that she didn't understand how her medication worked but the doctors were too busy for her to ask:

**P8:** *Who will I ask because the doctors are always busy? Who will I ask?*

It seemed that participant P8 did not know where else to get the information she needed if she could not speak to the doctors about her prescribed medication. She later expressed that she tended not to ask

the dispensing pharmacists at the hospital pharmacy any questions about her medication either.

Not being able to get the correct information could result in reduced adherence due to lack of understanding. Makaryus & Friedman (2005) agreed with this notion and stated that adherence can be improved if patients had a better understanding of the proper use of their medication and the associated side effects. This could be achieved if healthcare providers could devote the necessary time towards allowing patients to ask questions about their treatment plans. However, in a setting such as the clinic where the doctors have to attend to many patients, there is not always enough time to have lengthy conversations with patients. In these instances, it is important that the available time be used efficiently (Crawford & Brown, 2010). Focus needs to be placed on the fostering of collaborative trusting relationships with the patient which may be achieved by directing questions to the patient about their general well being and not just about the disease or drug related questions. This may assist patients to feel more comfortable in the company of the healthcare provider and empower patients to be more assertive during their interactions with the healthcare providers thus helping them to ask questions when they need to.

In South Africa, a study was conducted about factors that contributed towards successful care in a paediatric HIV/AIDS clinic (Watermeyer, 2012). Patient-provider relationships and communication were among the listed factors that were identified as contributing towards successful care. Patient education and the assistance patients received from healthcare providers in terms of understanding the disease and its treatment were highlighted as issues that both parties saw as integral in an effort to promote adherence and provide optimal care.

The desire to learn more about their medication(s) was conveyed by a number of participants in this study. These were patients who were

taking their medication but did not fully understand the purpose for it and were aware of their limited understanding in this regard. Dowell *et al* (2007) emphasises the importance of ensuring patients understanding, within the context of the patient-centred approach. Patients often walk into a health consultation with their own understanding regarding anatomy, disease epidemiology and treatment, informed by personal experiences and cultural beliefs. This understanding may differ from the biomedical understanding of the healthcare provider. As a result, healthcare providers can take for granted the necessity to explain to patients the relation between disease, symptoms and treatment. Patients are also aware that they know less than the healthcare providers which can create a level of anxiety. P10 describes how despite being uncertain of the purpose of some of her medication, she takes it simply because it was prescribed to her:

**P10:** *It's so hard taking pills when you don't know what they're for...I was doubtful of taking them...but I thought that because they gave them to me at the hospital, it's best I took them.*

It was also evident in some of the interviews that some participants had not tried to approach the clinic staff with any of their questions. One such participant also mentioned that she had not been attending the clinic school sessions.

**P9:** *I'm not sure [what the pills are for]; I just know that they are for arthritis.*

**Interviewer:** *Have you ever asked?*

**P9:** *\*shakes head\**

**Interviewer:** *Why haven't you asked?*

**P9:** *I don't know. I can't give you a reason.*



Although she said that she could not give a reason as to why she had not asked the healthcare providers for clarification, she later expressed that “[her] mom said she must just follow the doctors’ instructions”. This could be indicative of the social and cultural hierarchy that exists between patients and healthcare providers, where patients do not necessarily feel comfortable enough to ask questions about their treatment. This hierarchy may effectively hinder communication between healthcare providers and patients, thus making it difficult to relay important information to patients. It may have been that participant P9 had a fear of or felt uneasy about questioning the authority of the healthcare providers.

This category shows the importance of effective communication and the establishment of collaborative relationships between patients and healthcare providers. Amongst the patients who were comfortable with directing questions at the healthcare providers, adherence seemed to be at a higher level than with those who did not or felt that they could not approach the healthcare providers. It can thus be argued, that in the context of this RA clinic, the establishment of better communication between patients and healthcare providers to increase patient understanding of RA and prescribed therapy could help to improve medication adherence levels of patients.

### Use of Technology

With increased exposure to technology, the increased use of smart phones and various types of media, it has become easier for people to access many forms of information. With regards to health and medication, the internet can also be used as a source of information (Chou *et al*, 2009). Access to the correct kind of information can have a positive impact on adherence, especially if questions arise between clinic visits when patients cannot access their healthcare providers to

ask for clarification. Suitable websites can be used to supplement information received directly from clinic staff.

**P11:** *The first time I was gonna get the pills...there's a sister, a nurse who explains, so she explained to me and whatever. 'Cause I'm inquisitive, whatever I didn't get, I just googled. Me and Google, we're friends.*

It is, however, also important to note that increased access to information also appeared to expose participants to information that misled them. This was evident with one participant who purchased complementary medications as a result of hearing about them from her community radio station.

**P13:** *I remember I bought capsules to prevent your blood from stopping...I bought them, yes. A doctor comes on the Jozi radio station. He spoke about them.*

This category is a reflection of the changes taking place in the society at large. People are gaining wider access to various forms of information, and thus may no longer rely solely on healthcare providers to provide health information. It may not be possible to monitor all the information that patients have access to, but it may be helpful if healthcare professionals could direct them to credible sources. These could include websites that patients could access through their phones or computers that would provide them with accurate, verified medical information. It is also important that healthcare professionals warn patients to be wary of information that may be inaccurate.

### Language barriers

The majority of participants were not first language English speakers. This could have made communication with the English speaking doctors difficult, especially once biomedical terms were introduced in

discussions about the medications (Levin, 2007b). Often such terms do not have a direct vernacular equivalent and even when the nursing sisters are available to interpret, some concepts need to be paraphrased instead of translated which can impair the intended understanding (Solomon *et al*, 2012). Conversely, there are terms used in vernacular languages that cannot be adequately explained in English which could have compromised the message being relayed to the doctors. One such challenge is the description of pain. In English, words such as *dull*, *sharp*, *piercing* and *throbbing* can be used to describe pain. These words, however, cannot directly be translated into vernacular languages. Instead, metaphors are used which could make it more difficult to get the desired message across (Semino, 2010).

Here, two participants describe their symptoms using metaphors to try and convey their experiences:

**P1:** *My hands are on strike. They toyi-toyi at night...When I'm in bed, I feel like the living dead. My bones don't feel like they're mine. I feel dead.*

**P18:** *I was feeling hot and cold at the same time. There was a heat coming from my bones...It's hot, almost like there's a fire burning in your bones. And then, they turn black...The rubbing together causes pain, it causes that heat and causes the bones to be shapeless.*

Some participants used the term 'nyoko' to describe the side effects that they were experiencing. This is a term that anatomically refers to both the gall bladder and bile. As a condition or side effect, it has no English equivalent. *Nyoko* or *inyongo* are common phrases used to describe an array of symptoms such as GIT distress, dizziness, fatigue, headache and a general feeling of being unwell. Often, it is treated traditionally by inducing vomiting with salt water, or with laxatives to "clean out" the body. These are practices that can reduce the desired concentrations of prescribed medicines because induced vomiting and

diarrhoea can force the body to prematurely eliminate medication before it has been absorbed from the gastrointestinal tract. This may potentiate treatment failure by virtue of low drug concentrations in the body.

Adherence can also be negatively affected, especially if patients discontinue use of a particular drug that they suspect to be the cause of *Nyoko*.

Here, participant P2 responds to a question about the side effects she experiences from the RA medications:

**P2:** *The pills give you Nyoko.*

She also explained that she “reduced [her] *Nyoko* by drinking lots of water and taking it out”.

This category depicts the need for cultural sensitivity in the interactions between patients and healthcare providers. Healthcare provision exists within a context of increasing cultural diversity.

In a country as culturally diverse as South Africa, it is often the case that the healthcare provider and patient do not have the same cultural background. As a result, both parties have different cultural outlooks which play a role during their interactions. Kai *et al* (2007) describes how it can be disempowering to the healthcare provider, and somewhat reduce their social authority when they do not understand the cultural and social contexts of their patients. Daniels & Swartz (2007) also describe the anxieties felt by healthcare providers when faced with diverse cultures.

Levin (2006) spoke about the necessity of overcoming language and cultural barriers between patients and healthcare providers. The study suggests that healthcare professionals need to be trained and educated about the common cultural practices and languages used by the

populations they serve, and also maintain an openness to learning about their patients' cultural backgrounds. This may make it easier to promote effective communication, and possibly improve adherence rates.

### **EXPERIENCE OF HEALTHCARE SERVICES**

This theme describes the experiences of the patients at various points within the context of the South African health system. It explores how patient's encounters with public health services can contribute towards adherence behaviours.

The theme is divided into three categories:

1. Local healthcare experience.
2. Out-patient RA clinic experience.
3. Hospital pharmacy experience.

#### **Local healthcare experience**

The majority of participants were referred to the tertiary hospital from primary healthcare facilities. This process was often long and gruelling and caused delays in the diagnosis of RA, thus allowing the untreated disease to progress. Repeatedly, many participants sought help at their local primary healthcare facilities but did not receive the care they required. In particular, they were given anti-inflammatory and analgesic drugs which only allowed for short-term relief. This may not have directly affected adherence, since the correct medication had not been prescribed yet, but it did reduce the confidence and trust of the participants in the health service.

Various studies have shown that trust is a key component in medical interactions between patients and healthcare providers (Ozawa

&Walker, 2011; Graham *et al*, 2010; Gilson, 2003). These studies have shown that patients are more likely to trust and continue to heed the advice of healthcare professionals if they believe that their health related needs are being met, and if their quality of life improves as a result of the healthcare provider's interventions. Conversely, when patients felt that their needs were not being met, they lost trust in the healthcare providers and would no longer seek their assistance.

Participant P13 described her experience of her local primary healthcare facility and how she came to lose trust in their services:

**P13:** *I had gone to the clinic and they had done nothing. I stayed at home and did what I could do for myself.*

She explained that she stayed at home and sought no medical help until she was immobile and bedridden. Once she reached this debilitated state, she began to seek help from different clinics until she was referred to the RA clinic. Participant P13's actions are congruent with the results of a study conducted on the help-seeking behaviour of people with chronic hip or knee pain (Thorstensson *et al*, 2009). In this study, it was found that even though patients may experience extreme pain, immobility and disability were the factors that were most likely to cause patients to seek medical help. Unfortunately, disability occurs once RA has greatly progressed and medication may not be able to completely restore mobility at this stage.

It was also common for participants to seek help from local private doctors, most of whom were general practitioners. Even though they were trained and qualified medical doctors, they were not rheumatologists and, as such, may not have been equipped to identify RA as the cause of the patients' pain. Failure to refer patients to the correct professionals also resulted in the patients' conditions deteriorating.

Here, P11 describes her experiences. It was only in 2010 that she was diagnosed with RA:

**P11:** *It started in 2003 'cause I guess they didn't really know that it was RA 'cause they sent me for physiotherapy 'cause they kept on saying that maybe I'd fallen and I can't remember or I don't wanna remember, you see...I had medications, I had a cast for like three weeks. It was painful 'cause by then my hand was swollen. It was scary. So from 2003, I was on and off doctors 'cause, clearly, they didn't know what was wrong with me...So I stopped.*

This participant also experienced a loss of trust in the healthcare providers because her needs were not being met, even though the healthcare professionals had been implementing various interventions. She still felt that her quality of life had not improved.

This category reveals the need for trust to be present in the interactions between healthcare professionals and patients. This trust is a result of patients feeling that their needs were met at a time when they were vulnerable and decided to seek the help of health professionals, as well as a confidence in the prescribed medication. Trust can lead patients to follow the advice of health professionals, thus it can lead to patients being more adherent when treatment is prescribed (Ozawa & Walker, 2011; Graham *et al*, 2010; Gilson, 2003).

The cases in this category also reveal possible flaws in the structure of the South African health system and the training received by healthcare providers. Both participant P11 and P13 were diagnosed many years after they first started experiencing the symptoms of RA. Even though they had sought help, the primary healthcare givers they had consulted were unable to correctly assist them. This may be because Rheumatology is a specialist course that is not greatly covered in the general curricula of health science education. Perhaps the primary healthcare practitioners themselves did not have the necessary

knowledge to identify RA and refer these patents to rheumatologists. It may thus be of benefit to implement mechanisms that will aid primary healthcare professionals to identify RA sooner.

#### Out-patient RA clinic experience

Once patients had received the referral to the tertiary hospital, they gained access to the rheumatologists at the RA clinic. There, they were reportedly able to receive the correct medication. All of the participants expressed appreciation for the assistance they had received from the clinic staff and for the manner in which their quality of life had been improved.

Here, two patients describe the impact that the RA clinic has had on their lives and those of the other patients:

**P12:** *The sister who works with the pills has helped many patients, especially those who can't read and just took the medication...The clinic has helped a lot.*

**P15:** *They have helped me. When I got [here], I couldn't do anything. I can walk now. I can wear high heels.*

The health related needs of these patients had been met and thus they trusted the advice and treatment that they received at the RA clinic. Both these patients prove the theories of Ozawa & Walker (2010) and Gilson (2003) to be true – patients need to feel that they can trust in their healthcare providers and the treatment strategies that they recommend.

In most cases, the participants with co-morbidities had all their medication prescribed by the doctors at the RA clinic. This helped the doctors to keep track of what medication the patient was on and to prevent potential drug interactions.



One patient who also suffers from epilepsy, however, attended both the epilepsy and RA clinics. She thus had two separate files which meant that the RA doctors could not keep track of all her medication. As a result, she was receiving two different amitriptyline containing products from both clinics which effectively meant that she was overdosing on this medication. Amitriptyline has a registered indication of neuropathic pain but is also often used for the off-label indication of chronic pain. The off-label indication may have been the reason she had been prescribed the drug at the RA clinic.

**P16:** *They (epilepsy clinic) give me the same thing I get for arthritis... [The RA doctors] gave them to me and then they also gave them to me.*

This may jeopardise her health as the drug is known to cause side effects such as blurred vision, blood pressure changes, muscle tremors and may even precipitate epileptic seizures, cardiac effects and sedation, in high doses (Gibbon *et al*, 2008).

This category highlights the benefits of having a clinic dedicated to specific conditions where patients can access the appropriate healthcare providers and receive the correct information about both disease and treatment. It may be easier to have a positive impact on patients' adherence to chronic prescribed medication when there are specialist healthcare professionals at their disposal. It is, however, important that the medical specialists have the correct and complete information about what medication patients may be receiving from other clinics. This may minimise the incidence of avoidable drug related problems and incidences of duplicate prescription.

#### Hospital pharmacy experience

All the participants collected their medication from the hospital pharmacy. At the pharmacy, they come into contact with trained pharmacists, whose job it is to elicit information regarding the correct

use of medication. The majority of patients explained that this service was not being provided and they were not receiving any form of counselling from the pharmacists. Insufficient counselling therefore may have led to various misunderstandings regarding the manner in which doctors had prescribed that patients should take their medicines.

During an interview, it became apparent that one participant had been taking double the prescribed dose as a result of not understanding the dosage instructions. She had been prescribed 12.5mg daily of Ridaq. It seemed that for some months, the pharmacy had had no stock of the prescribed 12.5mg tablets so she was instructed to take half of the 25mg tablet. In other months she was given the 12.5mg tablets. She saw these as two completely different preparations so she took both of them. Her adherence to the prescribed instructions was thus reduced. As a result of taking double the prescribed dose and also because she took a diuretic agent at night, the patient complained of nocturia (urinating at night) and being unable to sleep well at night. Fortunately, this is a problem that could easily be dealt with and would not jeopardise her health in the long term.

**P10:** *I take [half of the 25mg] in the morning and the [12.5mg] at night.*

The amount of time spent waiting at the pharmacy was a complaint raised by many of the participants. In one case, the participant paid someone to collect her medication because she was unhappy about the amount of time she had to spend waiting to receive service. As a result, she did not receive education and counselling and this could negatively affect her adherence.

**P15:** *You know the pharmacy, it's just that there is nowhere for us to report. I don't know where to report it. We get there early in the morning, before the people who work there. We sit there, we're given numbers. They will call out the numbers after you, before you get called up, especially those of us with many pills. It's as though they push them*

*aside, I don't know what happens. There is an express queue. Their line moves fast. Those of us with many pills never get called up. What goes on in that place is not nice. I don't understand it.*

**P20:** *The pharmacy? It's a bad experience. [We] sit there a very long time, really. Every time, I don't usually go there and then I send someone. I pay someone to come and fetch my medication for me. Uh, the pharmacy, they need to do something about that place. Why can't they keep our medication here [at the clinic]?*

There was only one participant who, although dissatisfied with the service at the pharmacy, indicated that she felt that the pharmacists were doing the best they could to serve each patient.

**P18:** *Those people (pharmacists) work. There are a lot of us [patients]. They work. Even if they get annoyed, they're people. They work.*

This category highlights some of the system errors involved in hospital pharmacy practice in South Africa. The hospital pharmacy provides a service to all the hospital wards, as well as the patients from various out-patient clinics. Unfortunately, the ratio of pharmacists to patients is such that the pharmacy cannot provide a speedy service, and in most cases, limited time serves as a barrier to effective communication about the medicines being dispensed. This is another example of the insufficient healthcare resources and personnel within the public healthcare sector (Stuckler *et al*, 2011; Harrison, 2009).

From the accounts of many participants and upon perusal of their pharmacy records, it appears that there was often a shortage of many products that had been prescribed to patients. This would have decreased the adherence levels of patients as they could not receive their medication.

This chapter has described the numerous factors that can influence adherence both positively and negatively. It has highlighted areas where

interventions may be put into place to improve the medication taking practices of patients. This chapter has thus shown the complexity of adherence in the context of the participants' living experiences and interactions with medication, healthcare providers and the healthcare system.

## CHAPTER SIX: DISCUSSION

The findings of this study show that prescribed RA medication can significantly improve the lives of patients and help them to regain their sense of independence. This study has also shown that adherence is a complex phenomenon that is affected by a variety of factors specific to each patient and their living experiences. The lack of patient understanding of RA and its treatment were also brought to light through the accounts of the participants. This knowledge deficit seemed to have resulted from a possible breakdown in communication between patients and health workers. In this section, the factors affecting patient adherence as identified in this study will be explored, with possible recommendations which may help to improve adherence rates. The limitations and implications of the study will also be discussed.

In 2003, the World Health Organization suggested that adherence is affected by five factors (Sebate, 2003):

1. Healthcare system or provider-patient relationship.
2. Disease.
3. Treatment.
4. Patient characteristics.
5. Socio-economic factors.

The findings produced in this study echo the suggestions provided by WHO as many of the participant interviews revealed issues which can have be placed into these five categories listed above. The findings provide a detailed description of the various issues that contributed towards adherence to chronic prescribed RA medication. These included the quality and effectiveness of communication between RA patients and healthcare providers, the attitudes of patients towards chronic medication, the daily experiences of life with RA and the lifestyle

changes necessary to incorporate daily medication, as well as the level of understanding patients have regarding RA in light of all the influences on their medication taking behaviour.

In addition, this study provides some insight into the role of adherence in the lives of patients with co-morbid chronic conditions. This study suggests that there is a level of prioritization of co-morbid diseases, based on the perceived risks associated with each disease. This insight indicates the need for further research to be conducted to investigate medication taking principles of such patients, and the need for improved counselling by healthcare providers regarding each chronic condition.

When looking across the entire data set, there were three aspects of living with RA that emerged as major themes amongst all the participants interviewed:

1. Pain and disability.
2. Medication and medication taking.
3. The need for more information.

These were the issues that seemed to have the greatest impact on the patients' level of adherence to prescribed medication. These issues also provided insight regarding where healthcare providers could intervene to assist patients and thus promote increased adherence levels.

### **PAIN AND DISABILITY**

Pain can be described as an “unpleasant sensation experienced when nociceptors are stimulated. It is individual and subjective with a physiological and emotional component. Pain ranges from mild to agonizing, but individual responses are influenced by factors which include: information about cause, age, whether acute or chronic and pain tolerance” (Brooker, 2003. p219). This definition agrees with

Semino (2010) who further stated that because pain is so subjective, it often becomes frustrating for individuals to sufficiently describe their pain, especially chronic pain as experienced by RA patients. For this reason, metaphors are used as a means to better communicate the severity of the pain to a second party, the health worker.

Every patient interviewed expressed the severity of the pain they felt as a result of having RA. In some case, participants stated that they had difficulties with explaining the exact nature of the pain to another person such that the other could fully comprehend what it felt like. This presented problems for the patients when they sought medical help and had to describe to healthcare providers how they were feeling. Many of the patients relied on narrative means to explain the context of their pain and its influence on their living experiences.

Greenhalgh & Hurwitz (1999) described the importance of narratives in health practice. Narrative is sometimes the only way that a patient can express to a healthcare provider how and what they are feeling. It gives insight into what the patient perceives to be the problem and what their desired outcomes may be. In the context of this study, the use of narrative and socially rooted metaphor were often used to describe pain, such as with participant P1 who used the analogy of toyi-toying (a type of South African dance, usually used in active political protests) to describe the reluctance of her hands to function normally. Had she used this reference in a consultation with a healthcare provider, that healthcare provider would first need to have some level of cultural sensitivity to understand P1. One needs to be familiar with the historical, political and social contexts that exist in South Africa to understand a term such as this.

Perhaps the lack of information about the cause of pain as well as possible language barriers may have further compromised patients' ability to describe the pain to healthcare providers, especially during

visits to primary healthcare facilities. This may have led to the failure to appropriately treat the pain, and the amplification of negative perceptions that were expressed by participants about the primary healthcare system. Based on participant accounts, communication regarding the degree of pain and nature of the disease was most compromised at the primary healthcare level.

The primary healthcare setting in South Africa often reflects the shortfalls of the public health sector as described by Stuckler *et al* (2011) and Harrison (2009). Often, these facilities are understaffed and have resource shortages which can reduce staff morale. This creates an environment that is not conducive to the provision of good quality healthcare to patients seeking help at the facility.

Although the primary healthcare context was not investigated in this study, the patient accounts seemed to indicate a lack of information available to primary healthcare workers regarding the correct way to manage a patient presenting with symptoms of RA. This was expressed by a number of patients who said that they got the impression that the healthcare providers at primary healthcare clinics could not help them and, as a result, they were incorrectly treated. It was also expressed by one of the doctors in the RA clinic that there is a need for primary healthcare workers to gain better access to screening facilities or means of identifying early RA and the urgency to refer these patients to rheumatologists. Herein lies room for interventions to increase patients' confidence in the primary healthcare system and promote early detection of RA to allow for prompt exposure to the correct treatment. This is also an area that provides room for increased education to patients suffering from chronic pain. Patients need to feel empowered so that they can continue to seek medical help until such time as their health related needs are met and an accurate diagnosis can be identified. This will help to prevent avoidable rapid disease progression.



Along with increased chances of disability and disease progression, pain is the major consequence of non-adherence to RA medication. All the participants expressed how debilitating the pain could become and how much pain became a focal point in their lives. Many of them stated that the fear of experiencing further pain often motivated them to adhere to their medication. It seemed that avoidance of pain and disability was the factor that contributed most towards promoting adherence amongst the participants. This result is similar to that of Thorstensson *et al* (2007) who found that immobility and disability were amongst the biggest reasons why patients sought medical help and were most likely to adhere to treatment.

Healthcare professionals need to be able to identify patients presenting with symptoms of RA early so as to prevent these experiences of debilitating pain and disability. Pain assessment scales and guidelines might prove useful, such as those developed by the British Pain Society and British Geriatrics Society (2007) (*Appendix M*). The scales work similarly to the algorithmic criteria developed by the ACR and EULAR to determine a positive diagnosis for RA (*Figure 1*) (Clements, 2012). A numerical value is assigned to each symptom that the patients experience, and the higher cumulative values indicate that a referral to rheumatologists may be necessary.

Because of the differences in the literacy levels and linguistic and cultural contexts between South Africa and Britain, these scales may not be suitable for use in the South African context. However, these scales could be adapted to include exploration of patients' use of culturally sensitive narrative and metaphor, and used in the South African primary healthcare system to assist healthcare providers in identifying pain that requires referral to specialist doctors such as rheumatologists. Dowse & Ehlers (2005; 2004) have proved that pictograms can successfully be used within the South African context to explain medication taking instructions and thus improve adherence rates, but such tools do need

to be attuned to cultural nuances. Pictograms could also be incorporated into the pain assessment scales.

Pain assessment scales may not be as definitive in diagnosing RA as screening tests, but because they require less expensive infrastructure, they may be easier to implement into South African policies and treatment guidelines. Although the British guidelines are specifically for geriatrics, they can be adapted to suit all patients presenting with similar symptoms. The assessment scales can be filled out by the health workers, so that illiterate patients will not be disadvantaged, and include questions relative to the seven diagnostic criteria for RA (Ncayiyana *et al*, 2003). More research needs to be conducted on the possibility of adapting such scales into the South African public health sector.

The use of specific guidelines would make it easier for primary healthcare providers to identify chronic pain in patients. The early detection of patients needing referral will, potentially, lead to early diagnosis of RA which may decrease the inappropriate prescribing and dispensing of NSAIDs and corticosteroids in patients requiring DMARD therapy. Studies have been conducted showing that improvement in the health services provided to patients will serve to better the patients' quality of life and treatment outcomes (Lubeck, 2004; Scott 2004). In both studies, the need to treat promptly and focus on the optimal management of the physical and psychological aspects of RA is highlighted. It is imperative that the same philosophies be adopted into South African health facilities to improve the quality of care provided to patients, taking into account cultural and linguistic influences on the language of pain and the metaphors used to describe pain.

Secondly, it would be beneficial if healthcare providers acquainted themselves with the languages spoken by the people they serve. In this study, it has been shown that the use of mother tongues enabled

patients to better express themselves because they are able to incorporate cultural and social references into their descriptions of living with RA. Levin (2006) also suggests that learning some of the language and background culture of patients may help healthcare providers to understand patients better, and thus the likelihood of providing the necessary assistance to patients would increase. Understandably, it is not practical or feasible for healthcare providers to become fluent in all eleven official languages spoken in South Africa, but it would be helpful if they learnt common phrases relating to diseases they encounter regularly and instructions they give daily. In the case of this study, if healthcare providers learnt words like *ithambo* or *lesapo* (bone), *kubuhlungu* or *go a opa* (referring to pain) or the use of terms like *Nyoko*, it may make communication with patients easier. Further research needs to be conducted to provide a more detailed understanding of the nuances of cultural metaphors within the South African health system.

These proposed interventions regarding the interpretation of pain could be fairly easy to implement and would be useful in health practice because they could promote better communication with patients, and early referral to rheumatologists. Although the understanding of pain descriptions does not directly affect adherence, which was the main focus of this study, it enhances understanding of patient circumstances and potentially promotes better management of RA. Tay *et al* (2011) and Haskard-Zolnierek & DiMatteo (2009) have shown the link between effective communication between patients and healthcare providers, increased understanding of the patient viewpoint and how these factors can lead to improved clinical outcomes for patients. This means that better communication and understanding of patient experiences may ultimately lead to improved adherence.

Early referral and better management, as explained, may lead to improved quality of life for patients. In practical terms, this means

reduced disease activity, the alleviation of pain and regained independence. Many of the participants in this study expressed how debilitating the RA associated pain and deformities became and how they had to rely on others to help them carry out undemanding daily tasks such as opening a tap. These accounts agree with those of a study conducted amongst a similar demographic group, where the difficulty in performing daily tasks ultimately led to social exclusion (Schneider *et al*, 2008). Although social exclusion was not a major theme encountered across the dataset, a few of the younger participants did mention that they could no longer enjoy certain social pleasures such as going to parties for fear of being judged because of the effects of RA. These younger participants, together with participant P15, who was excited about being able to wear high heeled shoes again, further emphasize the need for a patient-centred approach to healthcare. The desired outcome of patients need to be taken into account because patients may measure disease burden on their lives based on the social restrictions caused by RA, which are factors that a healthcare provider may not immediately consider as targets for treatment outcomes.

Many of the negative physical aspects associated with RA, however, were apparently mitigated by the proper use of the prescribed medications. It was unanimous amongst the participants that once they had received treatment from the RA clinic, the quality of their lives began to improve. Many of them regained the ability to execute daily household tasks and to fulfil their duties at work. This rendered them less dependent on others, thus, they regained their independence. As Schneider *et al* (2008) found, the regaining of independence was a strong contributor towards patients being encouraged to adhere to prescribed treatment.

It is clear from the participants' accounts that RA medication does help to ameliorate the effects of the disease. It is therefore imperative that health workers continue to reinforce the benefits of prescribed

medications and the necessity to adhere to it. Constant reinforcement, along with the alleviation of pain and improvement in quality of life will help to highlight the importance of adherence to patients. It is, however, important to respect the agency of patients and allow them to the right to be involved in the decision making process of how they would like to be treated. This means that the team of health professionals can advise patients on the benefits of adhering to the prescribed conventional medicine, and the possible dangers of not adhering or the use of additional complementary medicines, but may not necessarily make the decision on behalf of the patient.

It is also important to acknowledge the tensions that may result from increased patient agency. It is possible that patients who feel empowered to make decisions about their treatment regimen may experiment with treatments that could negatively affect their prescribed medication, such as those patients who were using alternative medicines. There needs to be a balance between encouraging patient agency and promoting trust in the professional advice of healthcare providers.

Effective communication, the formation of collaborative relationships and encouraging a patient-centred approach, as part of a move towards concordance, may help patients to feel empowered and allow them to make better informed decisions about their medication taking behaviours.

### **MEDICATION AND MEDICATION TAKING**

The introduction of medication into the life of an RA patient is inevitable. Various studies concur that early and aggressive treatment is necessary to reduce pain and prevent (further) joint damage and loss of function (Hodkinson *et al*, 2012; Simmons, 2011). It can thus be argued that the chronic medication is the quintessential part of RA therapy, and

adherence to it is crucial. This notion was well understood by the participants of this study unlike in a previous study where the participants acknowledged the necessity of medication but only as a short-term feature in their treatment journey (Kumar *et al*, 2011). These findings may be an indication that participants understood that the disease is incurable and that they need to be on medication for the rest of their lives, which displays an element of successful patient counselling and specifically disease counselling by the clinic staff.

Unlike other diseases such as HIV/Aids, RA does not have a standardised level of adherence that is necessary for the achievement of optimal clinical outcomes. Ideally, patients ought to be 100% adherent, but missing a few doses or taking certain drugs incorrectly may not drastically impair the patient's health. Treatment success and adherence rates, therefore, can be measured by the degree of disease activity. Thus, the patient retains their right to agency because they can choose how adherent they will be to the doctors' prescription and as such, control their disease activity (Wagner *et al*, 2005; Mead & Bower, 2000).

Wagner *et al* (2005) and Mead & Bower (2000) acknowledge the notion that health status can be improved by the correct use of prescribed medication. However, they also state that effective patient self-management is also an essential part of the achievement of improved health related quality of life. This patient-centred approach requires that a team of healthcare providers serve as the support system to enable effective patient self-management. It is thus important that health workers communicate to patients the importance of adherence and achieving low disease activity so as to assist patients with the decisions they make regarding their health. The patient-centred approach thus advocates that the patient is an integral part of the decision making team when it comes to matters of their own disease management and treatment.

The patient-centred approach may be ideal for patients such as those who participated in this study. Many of the participants showed that they were proactive in their approach to RA. They described how they had experimented with other drugs, asked the advice of other patients, requested drugs from private pharmacies and approached the rheumatologists to ask for additional information and clarification regarding their treatment. These patients proved that they were not passive about their approach to RA but rather that they were assertive and prepared to take charge of their own health.

During the interviews, most patients stated that they took their medication because they recognised it as important for their well-being. Upon comparison of the interview accounts with the medical records reviewed, it became apparent that not all the patients were taking their medication as had been prescribed by the doctors. The question then becomes why patients do not adhere to treatment. From the health worker's perspective, it may come across as patients being reckless about their health (Kumar *et al*, 2011). But from the patients' point of view, this study has shown that there exists an intricate set of challenges that may prevent them from taking medication exactly as prescribed or that may lead to them experimenting with drug regimens. In this study, these challenges were at times self-imposed, such as patients who consciously chose not to take certain drugs even though they understood the importance of that particular drug. In most cases, however, the challenges were a result of factors beyond the control of the patient, factors which the health workers had the ability to amend such as furnishing patients with the necessary information when dispensing drugs, or systemic issues related to stock availability. Here again, the findings reveal areas where health workers can intervene to help increase adherence rates amongst patients.

Enhanced counselling about the medication(s) specific to each patient is perhaps the most essential intervention. This calls for better

collaboration between the clinic and pharmacy staff. Studies have been conducted to draw attention to the benefits of having the pharmacist as a committed part of the patient's support system and the healthcare team, especially in chronic diseases (Ramanath *et al*, 2012; Govender *et al*, 2011; Jameson & Baty, 2010). These studies have demonstrated that increased pharmacist assistance increased the patients' understanding of medicines and their use which led to better adherence.

The clinic which was the research site for this study, as previously stated, runs a counselling 'school' where they often invite various other professionals such as occupational therapists and physiotherapist to address the patients. They currently do not have a pharmacist who comes in to address and educate the patients about their medication. All the medication counselling has been the responsibility of the senior sister in the clinic. Although a number of the participants indicated that they felt the sister provided useful counselling, she cannot always reach every patient and address their specific needs. It may be helpful if her services were augmented with the addition of visiting pharmacists at the clinic 'school' to address medicine related problems.

Setter *et al* (2009) showed the effectiveness of having collaboration between nurses and pharmacists to address patient discrepancies regarding medication. The establishment of a team of all the health professionals involved, as well as the patient, will share the responsibility of adherence and possibly make it easier to promote. This will increase the number of well-informed sources in the clinic that can be consulted about drug treatment and hopefully also increase the number of opportunities for providing drug information to patients. Overall, it may reduce the tendency for patients to share (incorrect) medication advice amongst each other, therefore reducing instances of avoidable adverse effects.



It is also important that, along with the drug information sheets that are given to patients upon the introduction of a new drug into their regimen, doctors use the available time more efficiently (Crawford & Brown, 2010) when speaking to patients about their medicine related problems so that these patients can be identified and handed over to the counselling staff. As seen in this study, the involvement of a team of health professionals devoted to assisting patients with their adherence to treatment is particularly necessary for patients with co-morbidities as there was an apparent lack of counselling about their co-morbid conditions. Counselling during their consultations with the doctors was reportedly directed primarily towards RA and the other conditions were not discussed at the same length. This may have been the reason why the medication taking accounts of the participants with co-morbidities were not always congruent with their medical records.

The gaps in patients' understanding of their treatment indirectly increased their tendency towards resistance to taking all their medication because the other conditions seemed less important than RA. This argument is supported by recent studies where it was shown that patients have a preference for taking as little medication as possible, so a 'less important' disease is a means of justifying why they can reduce the number of medicines they have been prescribed (Pound *et al*, 2005; Townsend *et al*, 2003).

These studies also describe the phenomenon of passive acceptance of medication where patients simply adhere to their prescriptions without questioning why they are taking the drugs. These studies also describe a more flexible group of patients who do not passively accept their prescriptions, but who actively consider the pros and cons of each drug. The participants in this RA study seem better described by the second group identified. The participants were seen to consider adverse effects, perceived benefits of therapy and relevance of therapy before they made decisions to adhere to treatment regimens. Although this can be

seen as a positive move in terms of patients taking responsibility for their health, it can be dangerous if, because of insufficient information, patients deem certain drugs unnecessary and subsequently do not adhere to therapy.

Effective communication is essential for making sure that this problem be remedied by counselling patients with co-morbid diseases about the diseases and the various drug therapies. The effect of patient beliefs on adherence has also been researched and it was found that patients who strongly believe in the necessity of taking their medication are more likely to adhere in the long-term (Neame & Hammond, 2005). Counselling and improved patient education, especially with patients who have complex drug regimens, may lead to a decrease in the tendency towards resistance to certain treatments that was apparent amongst participants.

Self-medicating was another problem raised by the participants that could negatively affect their adherence. Use of medications, complementary or conventional, that have not been prescribed presents its own set of dangers that patients may not be aware of. These dangers include drug interactions, where the additional drugs interfere with the pharmacokinetics and/or dynamics of the prescribed medication. This can result in exacerbation of side effects due to increased toxicity or treatment failure due to altered absorption, metabolism or excretion of certain drugs. In both instances, therapy is compromised, therefore, patients must be advised against self-medication.

The use of complementary medication was expressed by a few of the participants, and the number of participants who referred to using such remedies was less than the research predicted which may be a result of under reporting by the participants, or it may be an indication of the growing confidence in the prescribed medication and the doctors at the

clinic (Peltzer, 2009). Efforts are being made towards their regulation but complementary medicines still present difficulties as health workers often have little idea of the contents of these medicines and how they will interact with prescription drugs. They are also readily available in communities and on open shelves in retail stores and pharmacies, as expressed by participants, and it is therefore difficult to regulate the purchase of such products. Better communication with patients and education about the dangers of such remedies needs to be reinforced so that patients are made aware of the potential dangers.

Another form of self medicating mentioned by participants was the use of over the counter (OTC) and prescription drugs by patients which they purchased at private retail pharmacies. It seems that because they are easily accessible, participants view OTC medication, such as Paracetamol, as safe and hence are not as cautious as they should be when purchasing and consuming them. Evidence suggests that misuse of OTC medication can result in severe side effects and even death, however, this study produced findings that indicate that patients may not conceptualise drugs and the consequences of their usage the same way health professionals would (Lopez, 2009; Cohen, 2007). It appeared that participants did not view OTC products as drugs in the same way that they view the “more dangerous” higher scheduled medicines. It needs to be reinforced to patients that even though they are easily accessible, OTC products are medicines and can be dangerous if misused.

Patients also need to be educated about the dangers of purchasing prescription medications without prescriptions. Although the issue of pharmacists illegally selling prescription medication to patients without prescriptions, as though they were OTC preparations, is one that needs to be addressed, patients also need to be warned against attempting to buy prescription drugs. It may help if doctors constantly explained to patients the reason why they discontinue the prescription of certain

medications so that patients understand the decisions behind the changes in their drug therapy. This information may decrease anxiety and help patients to adhere better to their prescriptions. This may also help them to feel as though they are a bigger part of the decision making process, therefore placing more responsibility on them about their health. This may trigger better decision making on their part regarding experimenting with prescribed therapy.

### **THE NEED FOR INFORMATION**

Amongst all of the study participants, it was noted that there are various aspects of their health knowledge where additional information was required to help them to make better decisions regarding their health.

The clinic provides patient information leaflets concerning medicines but a recent study conducted amongst RA patients found that patients preferred receiving oral information from peers and health professional regarding their medication, as opposed to written information (Zwicker *et al*, 2012). It was also found that the development of support groups was a feasible way of addressing non-adherence in RA patients. Homer *et al*(2009) also found that group sessions were a practical and time-efficient way of educating patients about DMARDs, using specialist nurses. They found that group counselled patients had better outcomes in terms of adherence and drug continuation rates. Because the clinic in this study may not have enough specialist nurses to run these support groups, it may be helpful to train 'specialist/expert patients' to oversee the support groups (Griffiths *et al*, 2007). These can be patients who have had had RA for a number of years, have experience with the medication and have been identified by the clinic staff as being adherent to therapy. Such patients may be more approachable as they could have gone through similar cultural and social experiences.

On a global level, the World Health Organization has shown support for the Chronic Care Model (CCM) and the Innovative Care of Chronic Care (ICCC) framework (Epping-Jordan *et al*, 2004). These are models that have been used in other countries such as Botswana, Morocco and Canada to try and reduce the burden of chronic diseases. The framework has three levels: Micro (patient and family), meso (healthcare organization and community) and macro (policy). The clinic can work on the macro and meso levels which focus on the distribution of accurate information and provision of sufficient support to produce a community of knowledgeable people who are prepared and motivated to fight the burden of chronic disease. This means producing patients who are adherent, and have a solid support system to aid in their endeavours. Again, this can be achieved through the proposed support groups.

It may also be helpful if the clinic created posters or videos, in various official languages, about RA and the treatment and displayed these in strategic places around the waiting area. These are sources of visual information, which may promote passive learning as patients can view them at their leisure while waiting for their consultations with the doctors. If patients are confronted with these on a regular basis, they may draw some additional knowledge from them. The posters and videos can also serve as material to initiate conversations in the group sessions. It may also be a good idea to put up information directing patients to credible sources of information at times when they are between clinic visits. These included internet sites that patients with access to internet services can consult. Provision of these sources may help to deter patients from seeking advice from less credible sources such as community members, as was reported by some participants.

### Summary of Recommendations

- The use of pain assessment scales in primary healthcare facilities to allow for a more efficient referral system.
- Health workers need to acquaint themselves with disease specific terminology in the language of the population they serve.
- Reinforcement of the benefits of prescribed medication to patients.
- Better collaboration between clinic and pharmacy staff to address the medicine discrepancies of patients.
- More dedicated time to counselling about treatment of co-morbidities.
- Improved counselling about the dangers of self-medication.
- Increase in the number of posters within the clinic.
- Distribution of information about resources with accurate disease and medication information which patients can access at any given time.
- Establishment of support groups.

### **IMPLICATIONS**

#### Implications for practice and policy

This study serves as a starting point from which the RA clinic staff can work towards improving the services they provide. The proposed recommendations can be used as a means to increase and improve communication with their patients and allow for constant feedback for their service. This study also highlights areas where collaboration is possible with other healthcare professionals. Ultimately, the clinic has the opportunity to set an example for the surrounding clinics in the hospital's out-patient department regarding how to afford patients the best possible healthcare. This implies that the idea behind this study can be used, in future studies, by any one of the other clinics to gain better understanding of their specific demographic.

The study also presents a challenge to the hospital pharmacy to improve its service due to all the negative feedback received from participants. It must, however, be acknowledged that the pharmacy context was not as extensively investigated as that of the RA clinic in this study. There may be a complex set of challenges preventing the pharmacy staff from offering the ideal services. Taking that into account, this study does indicate that the pharmacy staff needs to investigate and begin to revise some of their policies in an effort to provide a more efficient service to the numerous patients that they attend to. Also, this study has provided evidence that suggests the pharmacy could help to promote adherence at the RA clinic (and possibly the other clinics within the same vicinity) by collaborating with the clinic staff.

In terms of the greater South African health system, this study indicates the need for better infrastructure, training and education specifically for primary healthcare personnel so that they may be able to identify conditions such as RA, which require referral to specialists, more rapidly.

#### *Implications for theory*

Much of the literature cited in this study is based on European, American and Asian populations. Some research has been conducted in Africa as well, but not enough has been conducted on the African continent. Not many studies have specifically examined adherence behaviours and RA within the South African context.

This study explored adherence and the medication taking practices of a relatively small sample of patients, but the information that was discovered provides great insight into the perspectives and living experiences of these patients. The issues revealed in this study may be transferable to a wider demographic. The findings of this study contribute positively towards achieving a better understanding of the

issues, specific to this country, that influence the many in which patients interact with prescribed chronic medication.

RA is not a condition that has been widely researched in South Africa, possibly because it affects a very small percentage of the population when compared to epidemics such as HIV/AIDS and TB. This study reveals the impact that RA has on the lives of those affected by it and thus contributes towards the understanding of the greater population of patients within the South African public health system.

The study also provides greater insight into the concept of adherence amongst patients with co-morbid chronic conditions and how they appear to prioritise their various illnesses and the treatments for each illness.

#### Implications for future research

This study reveals an area of the South African health system that has not been fully explored; the views and opinions of patients regarding their diseases and treatment. Similar studies can be conducted for various other chronic or infectious conditions in order to understand the similarities or differences in the experiences of other patients and the RA patients who were interviewed in this study.

Research must also be directed towards understanding the complexities that surround adherence in patients who suffer from multiple chronic conditions and the effects of polypharmacy on their adherence levels.

The implementation of the recommended interventions could also serve as a basis for future research. This could help South African healthcare providers to better understand the people they serve and the quality of the service that they provide.

The pharmacy service context was not explored in this study. Future research endeavours could investigate the specific challenges that are



facing hospital level pharmacists in South Africa and begin to discover ways in which these challenges can be overcome.

### **LIMITATIONS**

The participants in this study were purposively selected. Random sampling could not be achieved as it was not possible to know in advance which patients would be present at the clinic at specific times. These patients were also returning to the RA clinic which implies that on some level that had a desire to remain adherent and continue their relationship with the clinic staff. As such, their medication taking behaviours would be better than those of patients who had defaulted treatment. Such patients were not investigated in this study,

The study also had a small sample size and was limited to patients who were willing to participate, however, data saturation was reached in the responses from participants which suggests that the study does depict an accurate representation of the experiences of patients at this particular RA clinic. There is, however, no way of guaranteeing that participants were completely honest with their responses although the relative uniformity of their responses and the achievement of data saturation indicates a level of truthfulness.

## CHAPTER SEVEN: CONCLUSION

The above findings and discussion reveal the complexity surrounding adherence taking principles within the RA patients and the out-patient clinic. There is evidence of social, cultural, linguistic, organizational and economic influences on the adherence and medication taking behaviours of the participants.

The study highlights the successes of the clinic context that have helped to improve the patients' medication adherence levels. The study does, however, also indicate areas where there is room for improvement and where systemic errors have led to a possible reduction in the adherence levels of RA patients.

This study also reflects many of the difficulties facing the South African government with regards to the public healthcare system. There is evidence of the effects of apartheid that are still present, 19 years after the instatement of the democratic government.

When juxtaposed against the state of the public health system, the RA clinic can be seen as a positive symbol of what may be achieved by other healthcare facilities if systems are put into place to focus on the needs of the patient. The clinic serves as an example that it is possible to begin to overcome some of the challenges that have burdened the South African health system in this post-apartheid era. Although there is still room for improvement, the clinic's concerted effort to educate patients about their disease and its treatment, and to form a positive support system from which patients can gain access to the correct medical information, appears to have impacted positively on the medication taking behaviours of their patients. In this regard, the clinic is a representation of what South African healthcare providers are capable of achieving.

The reports of the patients regarding their interactions with medications suggest that there is a great need for South African pharmacists to come to the fore and implement programmes that will educate patients about the correct and appropriate use of medicines. During their training, pharmacists are taught to be the custodians of medicines and to have great respect for the effects that medication can have on the treatment of chronic conditions. It would appear that in reality, the theory is not being adequately implemented into the practice of pharmacy. This may be due to the identified challenges that pharmacist face such as an inability to access all necessary drugs and an understaffed workforce that may not be able to serve the number of patients requiring their services. These circumstances can make it difficult to provide a good quality service, thus the ability to form collaborative and trusting relationships with patients may be hampered. Improved infrastructure and better incentives may also need to be provided to pharmacists in order to motivate and assist them in improving their services.

The findings also show the need to encourage a balance between patient agency and the shared responsibility of the patient and the healthcare team in improving the health related quality of life of RA patients. The participants in this study have proven that they are assertive and have an interest in gaining better understanding about their disease and its treatment. There is also evidence that patients with multiple chronic conditions need additional counselling regarding their health as a whole so as to discourage the tendency to view certain diseases as superior to others and thus prioritise certain medications over others.

Interventions and further avenues for research have been highlighted in this study because although the study adds an element to the existing body of research that did not previously exist, there are still elements requiring further investigation. This will help healthcare providers to gain a better understanding of the phenomena and contexts within

which patients must adhere. RA remains a condition that is under researched and more efforts can still be made to improve the lives of RA patients.

Overall, the study provides a description of the various factors which affect adherence within the chosen demographic. This study has demonstrated the various factors that affect the adherence rates of patients with RA, as described by the patients. The use of qualitative methodologies served to enhance the quality of this study and its ability to elucidate adherence practices in RA patients, where quantitative methodologies may not have served as well. The use of patient narrative and the process of thematic analysis helped to describe, in detail, the factors affect medication to prescribed RA medication, as described by the patients.

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### **LEGISLATION**

Medicines and Related Substances Act 101 of 1965

Pharmacy Act 53 of 1974

## APPENDICES

### APPENDIX A: SEMI STRUCTURED INTERVIEW SCHEDULE

#### FACTORS AFFECTING ADHERENCE IN PATIENTS DIAGNOSED WITH RHEUMATOID ARTHRITIS

#### INTERVIEW QUESTIONS

##### DEMOGRAPHIC INFORMATION

1. PARTICIPANT CODE: \_\_\_\_\_

2. DATE OF BIRTH: \_\_\_\_\_

3. GENDER: \_\_\_\_\_

4. DIAGNOSIS: \_\_\_\_\_

5. LANGUAGE OF PREFERENCE/ HOME LANGUAGE:

\_\_\_\_\_

6. CONTACT DETAILS:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

7. LEVEL OF EDUCATION:

\_\_\_\_\_

8. OCCUPATION: \_\_\_\_\_

\_\_\_\_\_

**HOSPITAL RECORDS**

Medication Prescribed	Doctor's Instructions	Patient's Report

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**RESEARCH QUESTIONS**

**1. TELL ME, WHAT SYMPTOMS LED YOU TO SEEK MEDICAL ATTENTION AND RESULTED IN YOUR BEING DIAGNOSED WITH RHEUMATOID ARTHRITIS?**

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**2. TELL ME ABOUT YOUR ILLNESS?**

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**3. WHAT DO YOU THINK CAUSED YOUR ILLNESS?**

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**4. TELL ME/SHOW ME, HOW AND WHEN DO YOU TAKE YOUR MEDICATION?**

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**5. WHAT THINGS HELP YOU TO REMEMBER TO TAKE YOUR MEDICINE?**

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**6. WHAT THINGS MAKE IT DIFFICULT FOR YOU TO TAKE YOUR MEDICATION?**

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**7. WHAT OTHER MEDICATION DO YOU TAKE, BESIDES WHAT THE DOCTOR HAS PRESCRIBED FOR YOUR RHEUMATOID ARTHRITIS?**

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**8. TELL ME, WHAT IS YOUR UNDERSTANDING OF THE MANNER IN WHICH YOUR MEDICATION WILL RELIEVE YOUR SYMPTOMS?**

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**9. TELL ME, HOW HAS THE INCLUSION OF YOUR MEDICATION IMPACTED YOUR DAY-TO-DAY LIVING EXPERIENCE?**

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**\*THANK YOU FOR PARTICIPATING\***

**APPENDIX B: MORISKY MEDICATION ADHERENCE SCALE**

**You indicated that you are taking medication for your (identify health concern, such as “high blood pressure”). Individuals have identified several issues regarding their medication-taking behavior and we are interested in your experiences. There is no right or wrong answer. Please answer each question based on your personal experience with your [health concern] medication. Interviewers may self identify regarding difficulties they may experience concerning medication-taking behavior.**

<b>(Please circle the correct number)</b>		
	<b>No=0</b>	<b>Yes=1</b>
1. Do you sometimes forget to take your [health concern] pills?		
2. People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your [health concern] medicine?		
3. Have you ever cut back or stopped taking your medication without telling your doctor, because you felt worse when you took it?		
4. When you travel or leave home, do you sometimes forget to bring along your [health concern] medication?		
5. Did you take your [health concern] medicine yesterday?		
6. When you feel like your [health concern] is under control, do you sometimes stop taking your medicine?		
7. Taking medication everyday is a real inconvenience for some people. Do you ever feel hassled about sticking to your blood pressure treatment plan?		

8. How often do you have difficulty remembering to take all your medications? **(Please circle the correct number)**
- Never/Rarely.....0
  - Once in a while.....1
  - Sometimes.....2
  - Usually.....3
  - All the time.....4



## **APPENDIX C: TRANSCRIPT BACK TRANSLATION REPORT**

### **Back translation Report of Transcripts for Interviews Conducted by Boitshoko Kobue**

The following Interviews were translated and back translated by me to ensure relevance in content:

**Interview 2:** The interview was conducted in Sesotho

- There was equivalence in standard English
- The interview conducted was accurately transcribed

**Interview 7:** The interview was conducted in IsiZulu

- Transcription is direct(word for word)
- No discrepancies noted between the translations most words had the same meaning

**Interview 10:** The interview was conducted in Sesotho

- There is equivalence of meanings between the two languages .i.e. Sesotho and English
- There is no discrepancies noticed in the translation

**Interview 13:** The interview was conducted in Sesotho

- The interview conducted was accurately transcribed
- There is no discrepancies noticed in the translations

**Interview 18:** The interview was conducted in Sesotho

- No discrepancies noted between the translations most words had the same meaning
- The interview conducted was accurately transcribed

There is indication that improvements as well as the upholding of qualitative and professional translations and transcriptions are displayed at all interactions.

Thank you

Keletso Mmoledi

## **APPENDIX D: SUMMARY OF INTERVIEWS**

### **P1-fruit and veg strike**

- Patient only on NSAIDs- not yet on DMARDs. Was on prednisone for a month.
- Self-medicated before seeking medical help.
- Warned by private doctor about self-medicating.
- Pain started in the joints of her hands-hands can't grip properly anymore. Then, it spread to her feet.
- Has basic understanding of "a tissue" being worn away causing the pain.
- Believes water, manual labour and lifting heavy objects caused RA... The way I see it, I think because I spent many years working as a domestic worker, doing laundry and ironing. Maybe that's when it started and I ignored it. I also think using water often, and electricity with ironing, caused it.
- Pain reminds her to take meds.
- Seldom forgets but being busy at work causes her to not take meds on time.
- Pain is elevated at night-can't cover herself with blankets.
- Still self-medicates. Buys Panado to make her Naproxen last longer-uses both when pain is severe... No, I've never taken such chances. Instead, I try to find a Panado and I take the Panado because I'm scared of taking two because maybe it's wrong...I just take a Panado when the pain gets too bad.
- Poor understanding of how the medication works. Seems not to understand the chronic nature of the disease.
- RA affecting efficiency at work, needs help often- worried about job security.
- Looks for pity at home. Feels sorry for herself but hated being a burden.
- Needs help going to the toilet at night (bucket). Hold on to burglar bars.
- My hands are on strike. They toyi-toyi at night.
- When I'm in bed, I feel like the living dead. My bones don't feel like they're mine. I feel dead.

### **P2-Gogo with nyoko**

- Has co-morbidities (DM, HT).
- Believes excessive use of water caused RA and working hard (was a domestic worker).
- Refers to herself as disabled.
- Has not linked the symptoms of HT to the disease. Co-morbidities may be a cause for confusion.
- Some discrepancies with regards to meds vs. what was prescribed- in patient records.
- Doesn't always understand which tablets are for which condition and what they do.
- Sometimes gives higher doses on Insulin when sugar levels are too high.
- First lost sensation in hands and then feet.
- Pains remind her to take meds. Daughter also helps.
- Forgets to take meds when stressed.
- Doesn't use traditional meds, homeopathics.
- Self-medicates. Buys pain meds at the pharmacy- pills she once was prescribed.
- Doesn't know how the medication works, just knows that it takes her pains away.
- Calciferol and prednisone cause her eyes to itch and water- strange side effect.
- Complains that the medication causes "nyoko".

### **P3-connected spinal cord**

- My bones are filled with cold.
- Co-morbidity (HT).
- Doesn't know what any of her medication is for- just takes it (WHY?)
- Identifies pills by their colour. Presented a problem between MTX and folic acid as both are small, round and yellow.
- Pain started in her hands. Couldn't bath or get dressed.
- Believes that the cold that entered her bones caused the disease but the weather doesn't seem to contribute much to the pain.
- Medication causes her to feel hot (hot flushes?). She needs to feel cold before she can sleep.
- Never forgets to take her medication-routine.
- Doesn't use other meds- scared of mixing.
- Medication causes her eyes to hurt and bloating.

#### **P4-coloured tswana**

- RA caused her to lose her job.
- Has a basic understanding of what each med is for.
- Appears to be very clear on her routine.
- Pain started in her hands, feet and knees- couldn't walk.
- Needed some prompting but understood the concept of cartilage being worn away.
- Thought RA was a disease for the elderly (she was diagnosed at 37), and that water contributed. But these were disproved by her personal experience.
- Was in denial after she was diagnosed. I didn't believe it... I even disputed it with the doctor.
- Doesn't forget to take meds. Nobody helps her to remember.
- Deliberately skips evening doses when she isn't in pain.
- Only takes RA meds.
- Once, she took bone medication that her mom had received from her cousin (who works in a hospital) but it made her sick, like she had an ulcer... I once took medication that I was told was for bones, given to me by my mother. She got them from my cousin who works at a hospital.
- Doesn't really understand how the medication works but she feels that it's working.
- Main side effect is the diarrhoea MTX caused.

#### **P5-mustard, garlic, lemon**

- Left out some of her medication-maybe she just forgot. Clear understanding of what dose to take when.
- Co-morbidities (HT, Cholesterol).
- Started in her hands and the feet, and general stiffness- constant burning sensation.
- Her performance of daily activities was hampered but she kept going because it has to be done.
- Admits the concept of WBC and RBC was explained to her and she seems to have a vague understanding of what it all mean. But, has no idea what would cause RA.
- Mentions use of water and hard work as factors that may contribute to RA.

- Displays confidence in her medication.
- Taking her meds has become routine. She had to discipline herself. Having the importance of the meds explained to her helped her to achieve this.
- Nobody reminds her.
- Admits to once having a bad attitude and being in denial about her RA which led to poor adherence when she was diagnosed... "I'm leaving this tablet. I'm not taking no medication." But then I saw that I was going backwards and getting all those pains and things. I said "this is my mindset, I'm making myself positive about my medication and I'm starting to take my things as they should be taken".
- About denial... [it was] denial. You look at your age and you're so young and you have a husband and all these things, and for you, having arthritis is something that you think you're over the wall, you're finished.
- Possibly shame? That was my thing that I would never say to anybody that I have arthritis. It was my secret. I didn't even really tell my husband that the Dr diagnosed me with arthritis.
- Self-medicates with a topical homeopathic remedy- mustard and garlic oil.
- Had never asked Dr- why she doesn't understand how the medicines work to relieve her symptoms. But she plans to ask now about her eyes and CQ.
- Major side effects- MTX and the nausea (drinks lemon water with honey), CQ and her itchy eyes.

### **P6-red beret (Moipone's gran)**

- Co-morbidities (Cholesterol, HT, DM)
- Has a clear system of how she takes her medication but it's not consistent with what the file states.
- Has so many pills, she forgets the names sometimes.
- Goes to different clinics for each condition.
- Her understanding is best with the RA and DM, and that medication. Much poorer with HT and cholesterol.
- Symptoms started in her feet then hands. Her hands are ok now since she takes meds.
- RA limits her daily activities.

- Takes her meds because it's the rules. And she has her husband to remind her.
- She doesn't forget but sometimes she just feels like taking a break... Sometimes you just want a break from them. You don't want any pills that day...You just tell yourself that you're not taking them that day and you'll just see what happens.
- Doesn't take other meds. Scared of traditional meds.
- Prednisone and MTX cause her to feel bilious. Aspirin causes reflux- she drinks lots of water.
- Over-all she believes that her medication has helped a lot.

### **P7-green skaftin**

- Appears to be very knowledgeable about RA meds, routine and what they do
- Co-morbidity (HT). Poor knowledge of HT and the meds. Later expresses that she isn't really concerned about it. File shows that it's uncontrolled at 197/113 and her compliance is questioned...In all honesty, I'm not as concerned about the high blood ones. I take them because they're my pills but it's not something that's on my mind. What's on my mind is this (RA)
- Waited a long time to get properly examined- experienced many symptoms she admits to not taking seriously, until her knee swelled up very bad and was operated on. Perhaps there was an element of denial because she had previously explained that she watched her mother suffer from RA so she should have been familiar with symptoms sooner?
- Admits to laughing at herself to avoid being stressed by the severity of her condition and how it impacts her life.
- At times she seems to blame herself for the deformities...I allowed this thumb [to get deformed]...I would even switch the way I held my pen so as to accommodate my thumb. That's how I felt comfortable but I was wrong.
- Has a good understanding of the immune system and its involvement in RA. She seems to be very interested in knowing as much as possible about RA... I attend workshops in Parktown. I read books/pamphlets. I want to know what it's all about. Even when I'm with the Dr, I ask questions about what's happening to me...What kind of disease is this that doesn't get better?
- RA seems to have a very big impact on her life. She seems to be conscious of it in everything she does.

- Remembers her medication because it has become second nature. She also describes a very well organised and labelled container in which she keeps her medication.
- Poor support system- her children help her when they have to but they are often upset about it.
- Goes to the Pharmacy when Bara is out of stock.
- Self-medicates with “Forever Living”. I tonic she buys, said to be for arthritis.
- Well informed about the purpose of each individual drug she takes for RA.
- Describes MTX as “a devil” when explaining the side effects she experiences...I’ll be vomiting, I’ll have diarrhoea, my mouth fills with saliva, I get a headache, everything goes wrong. Spectrapain causes nose bleeds if used excessively.
- Expresses concerns about chronic medication...It’s helped but at the same time I worry. I’m worried about what it’s doing to me. I don’t want to lie, it bothers me. I’m always on them. They have become my life. I ask myself because our bodies were made to fight for themselves. So now, what’s going on inside mine?

### **P8-I don’t take chloroquine**

- Didn’t recall all her medication, had trouble with some of the names and was not taking everything as prescribed.
- Uncertain about the purpose and manner in which most of her medication works. Possible link between these 2 points?
- Many of her medication was out of stock at the pharmacy at the time she went to collect her repeats so she seems to seldom have the full complement of medicines.
- Doesn’t take her chloroquine because it ruins her eyes... Oh chloroquine. You know, let me tell you the truth, before God, I don’t take it because it damages your eyes...I don’t take it, I’m being honest with you...I don’t take it at all but they give it to me. (Me) How did you hear that it damages your eye? Did someone else tell you?  
No, when they prescribe it, they refer you to St Johns (eye clinic)...the referral letter says it’s chloroquine...so I noticed then that it means they will damage your eyes.
- Her decision was compounded by rumours/ experiences of poor service at the eye clinic...There’s a lady I know who used to take them. She can’t see now...St Johns sometimes ruins us, honestly. I don’t know if

it depends on luck or not...But even my sister went to St Johns. They operated on her eye and it turned white. White!

- She first experienced trouble gripping and then swelling in her wrists and hands. People told her it was arthritis. She only sought help when her finger started to bend.
- RA hampered her performance of daily tasks...you can no longer do things the same way you used to. You work very cautiously so that you don't hurt yourself...Even bathing, that time when it was still really bad, I couldn't wash my face. I would wait for the day when the pains weren't as intense and bath then.
- About the pain...it feels as though someone is cutting you with a saw.
- Didn't receive any form of counselling but also seems to not attend the school provided by the clinic.
- She knows that RA isn't caused by water; she was told by her private doctor...He said it's a disease like any other, like sugar diabetes or high blood. It happens that it just falls on you.
- Her mother had ramatiki-this is an old term people used to describe a disease causing pain in the bones, probably derived from rheumatoid/ism.
- Pain and the fear of more pain remind her to take her medication. She has fallen into a routine and takes her medication even when she feels no pain. She never forgets.
- Doesn't know how her meds work. Never asked because the doctors are always too busy and she receives poor service at the pharmacy...
- Generic substitution- she comes back to the clinic to ask the Dr what the new medication is. This means that if she doesn't know the product, she won't take it until she returns to the clinic.
- Self-medicates with Lavida tea which she buys from sales people in her neighbourhood. She uses it for Nyoko.
- Overall, the medication has improved her quality of life.
- Side effects- constipation, ulcers. Not enough to cause her not to take her medication. Was taken off MTX because of the side effects.

### **P9-young giggles**

- Doesn't know the names of her meds, couldn't recognise the names when she saw them-had to use the pics.
- Not taking meds exactly as prescribed, most notable is her taking MTX and folic acid together.



- Dr's script no longer includes prednisone but it seems she is still getting it from the pharmacy and using it.
- Doesn't know what the medication is for. She has never tried to ask anyone or find out.
- Noticed painful joints mostly in her hands, then her knees. She used NSAIDs for a long time to relieve the pain.
- Turns out she did get the initial counselling from the sister where she learnt that the pain comes from her bones rubbing together as a result of a gel being finished between them.
- Knows it's not caused by water but doesn't know what the cause is.
- Pain reminds her to take her medication. She also sets alarms for her weekly doses.
- Sometimes forgets to take meds when she is too busy at work (waitress),
- Has not self-medicated since she was properly diagnosed.
- No major side effects but titralac makes her sleepy.

### **P10-Ridaq x2**

- I was not fluent in her home language, XiTsonga, so we spoke in SeSotho which we both understood.
- Had to stop working because of her RA.
- Couldn't recall all her medication but seems to be taking most of it correctly.
- Ridaq problem: Dr prescribed 12.5mg/d but she is taking 3 times the dose. It seems she was given the correct dose, and 25mg tablets which she was told to break in half by the pharmacist. So she is taking half of the 25mg in the morning and the 12.5mg at night. She complained of nocturia...I take [half of the 25mg] in the morning and the [12.5mg] at night.
- Various items on her script were out of stock at the time of collection.
- Says she would like to have her medication explained to her because she takes it but doesn't know what it's for...it's so hard taking pills when you don't know what they're for...I was doubtful of taking them...but I thought that because they gave them to me at the hospital, it's best I took them.
- Pain first presented in her hands, then shoulders, then feet.
- Associates RA with water and cold- what they Dr told her.
- Attends the school.

- Takes medication because it has improved her quality of life and she's afraid to cause further damage,
- Understands that she can't be cured.
- Never forgets.
- Does not self-medicate.
- Knows that meds are working based on how her body feels but she doesn't know how everything works.

### **P11-I was just miserable**

- Seems to have a good understanding of her medication and how to take them. Also has a good understanding of the disease.

It took 7 years for her to be diagnosed. By this time, her RA had become completely debilitating and she had to stop working... It started in 2003 'cause I guess they didn't really know that it was RA 'cause they sent me for physiotherapy 'cause they kept on saying that maybe I'd fallen and I can't remember or I don't wanna remember, you see...I had medications, I had a cast for like three weeks. It was painful 'cause by then my hand was swollen. It was scary. So from 2003, I was on and off doctors 'cause, clearly, they didn't know what was wrong with me...So I stopped.

- Age may have contributed...And I didn't it then that maybe, just maybe, it's something 'cause obviously arthritis you associate with old people.
- Both her hands and feet were affected. Daily activities were very compromised... To get out of bed would probably take me longer than 15-20 minutes 'cause I need to have a strategy of getting out of the bed actually. I found that I stopped sleeping on the bed 'cause it was harder to get out of bed than it was actually easier to sleep on the couch.
- Diagnosed herself using the internet before private Drs figured it out.
- It seems it got to a point when the pain controlled her life...I can't move without actually thinking about it 'cause I'm thinking if I move now, the pain is gonna come back. If I sit, the pain is gonna come back. Either way, I can't do anything 'cause that constant thing of pain. And I can't sleep. I can't walk around. I'm just miserable.
- Her story highlights the inefficiency in referral from primary health care facilities and private doctors when a patient presents with something that's beyond their expertise.
- Fear of pain returning...The pain I felt, I never wanna feel that kind of pain and, on a serious note, I don't wanna wish it on somebody.

- Pain and the desire to be self-reliant remind her to take her medication.
- It took her sometime to learn to incorporate her regimen into her daily life. It took some time to develop her routine.
- Side effects: heartburn and a rash(it has since been dealt with). The long list of possible side effects are what make her not want to self-medicate or mix her meds with anything else. She's afraid it may lead to further damage.
- Expresses dissatisfaction with pharmacy service.
- Counselling from the sister was very helpful. She also googles when she has queries regarding her medication.

### **P12- Dr Tickling**

- Co-morbidity (HT), seems less worried about it than RA.
- Taking her medication correctly.
- Generic substitution: Stilpane, Salterpyn, Spectrapaine.
- Pain first presented in her hands, shoulders, knees and ankles.
- Has family history of RA.
- Her adherence is promoted by the fear of what could be...If you don't take your treatment properly, you could become deformed. Yes, it bends your hands, it bends your feet, it bends your knees. You could find yourself deformed if you aren't careful. Pain also reminds her.
- Doesn't self-medicate...I'm afraid of the after effects because if they have after effects, who will I consult?
- Not clear on which pill does what exactly and as a result she doesn't notice any direct effects. She just knows that they are helping.
- Finds the school very helpful...The sister who works with the pills has helped many patients, especially those who can't read and just took the medication...The clinic has helped a lot

### **P13-Aloe**

- Lost job because of RA.
- Co-morbidity (HT)
- Could not recall all her medication even though she used her file. Those she mentioned, she seemed to know how to take them properly and for which condition.

- Her arm was twisted, she couldn't walk or grip, had morning stiffness and constant pain.
  - Initially, she self-medicated with NSAIDs.
  - About clinic services... I had gone to the clinic and they had done nothing. I stayed at home and did what I could do for myself.
  - She used aloe to treat herself - cultural!
  - Private Dr gave her injections and pills- only worked short-term.
  - Gives a detailed description of how her life had been compromised and how the medication allowed her to function better on a daily basis...I know where I used to be and what helped me.
  - Can describe the pain but uncertain about what's causing it.
  - Mentions ramatiki and the impact of cold temperatures. Aware that water is not the cause...That's a tough question because before, when such things affected our mothers, they said it was Ramatiki. They didn't know that it was arthritis...they thought it was caused by water because they did a lot of washing as domestic workers...They thought it was water and cold.
  - Never forgets and uses her fie to check herself.
  - Self-medication: lerumo la madi (tonic), herbs. She also uses blood circulation tablets which she heard about from a Dr on the local radio station.
  - Side effects: prednisone caused weight gain but she was taken off it. Found out it was prednisone from someone in the queue...Patients talk!
  - Expresses that she doesn't like that her life depends on the use of pills but she takes them anyway because they help her.
- Stops taking her medication sometimes just to see how her body will feel... Sometimes, though, I stop. Maybe for a day, I stop just to see how I will cope...I just want to know how my body would feel...Then it hurts and I sit. At night I think about taking them but I decide against it, just for a day.

#### **P14-Kea di kwatela**

- Lost job because of RA.
- For the most part, she's clear on what she takes, how many, and why.
- Understands the importance of calcium but doesn't take it because it's too sweet and causes her to vomit.
- Generic substitution, generics and trade names- naproxen, diclofenac and voltaren, prednisone. From what she says, it seems the pharmacy

sometimes hands over drugs that will have the same effect but aren't actually generics.

- Her RA was discovered "accidentally". She had a cyst behind her knee and while that was being treated, a scan revealed that she had RA.
- Attends respiratory clinic as well...has arthritis in her lung? File said chronic cough.
- Her RA is made worse by the cold, feels like a sprain. Believes it was either hereditary or she got it from working too hard. Water may make it worse, but it's not the cause.
- Pain reminds her to take her medication
- She gets angry at her pills then doesn't take them... Even when I feel pain, I sit with that pain. And it will hurt but I will ignore it and leave it that way. I tell myself that I don't want [the pills]
- Her life has been compromised when compared to other people her age. She's weary of negative treatment from others and their perception of her.
- Denial...I haven't accepted that I have arthritis in my life.
- Self-medicates with joint support pills and prednisone which she buys from the pharmacy illegally...How do you buy [prednisone] without a prescription? There are [pharmacists] that will sell them to you.

#### **P15-I need heat, I need cold**

- Believes she has the "cold" arthritis...It feels like I have ice inside [my bones]
- Co-morbidities (DM, HT, Choles)- not particularly clear on any of them.
- Left out lots of her medication. Has some understanding of what they're for.
- Bones have been eaten away because of too much acid...confusion with gout?
- Sometimes pain reminds her to take her medication but mostly it's because the Dr instructed her to. She never forgets.
- Sometimes skips days with her HT medication because Ridaq makes her dizzy. : I skip days with the high blood ones. I don't want to lie...I want to feel if the dizziness that I get is there when I don't take it.
- Self-medicates with a liquid preparation called "phila" for her DM.
- The biggest problem is the number of pills and the size of the Salazopyren.

- Impact...They have helped me. When I got [here], I couldn't do anything. I can walk now. I can wear high heels.
- Complaints about treatment at the pharmacy. It seems like they focus on dispensing to the people with shorter scripts first. RA patients are often left for last because they need lots of drugs...You know the pharmacy, it's just that there is nowhere for us to report. I don't know where to report it. We get there early in the morning, before the people who work there. We sit there, we're given numbers. They will call out the numbers after you, before you get called up, especially those of us with many pills. It's as though they push them aside, I don't know what happens. There is an express queue. Their line moves fast. Those of us with many pills never get called up. What goes on in that place is not nice. I don't understand it.
- Overdosing because of poor understanding...At times, when I get those hot flushes, I think it's cholesterol. Then I take 2 [tablets] and overdose so I can sleep.

#### **P16-The snake**

- Co-morbidities (allergy to Step & pen, HT, Epilepsy)
- Lost job because of RA.
- Recognises the names and knows how to take them but there were some issues and misconceptions as to why she takes certain things. I had to read the file for her, poor eyesight because of chloroquine, she says.
- Takes 2 Amitriptyline preparations- Trepeline from the epilepsy clinic and Tryptanol from RA...They (epilepsy clinic) give me the same thing I get for arthritis... [The RA doctors] gave them to me and then they also gave them to me.
- If she misses a weekly dose on the usual day, she waits until the next week because she was told not to switch days.
- Has trouble performing daily tasks. Seems to believe she has become annoying or a nuisance to people... You become a cripple and you suffer. Too much! You suffer. You suffer to the point where you irritate people. Even the children, when you keep calling out [for help] are like "oh gosh, my mother". But you can also see that they have had enough.
- The school helped to clear up a lot of issues. She knows that water isn't the cause. She believes diet contributed.

She describes her encounter with the snake... this story of the snake has cultural connotations. The snake is like the first manifestation of a series

of curses. It's a warning of sorts. It often appears to one person (at a time) and will never harm them but they can never call people in to show them the snake. She believes this is how it started and what led to the health problem. Carries on to describe how cancer runs in her family and she passed it on to her child... That snake! I was a child, so we slept on the floor. When I woke up and was folding the blankets, it was curled up as I was lifting the sponge/mattress. I, obviously, hadn't seen it because I was quiet and folding the blankets. When I wanted to call out to my brothers to show them what I saw as I lifted the sponge, [my throat] was this big! When I tried to speak, I couldn't. There was just a nasal sound.

- The sickness reminds her to take her medication. She used to forget before her epilepsy got treated (has absence seizures).
- Side effects: the chloroquine and its effect on her eyesight. She still takes it though, because it helps her. As with the rest of her medication which she takes even though it hurts to live off of medicine.

### **P18-Your bones become shapeless**

- Co-morbidity (HIV but not yet on ARV therapy).
- Seems pretty clear on how to take most of her meds and what they're for.
- About symptoms- I was feeling hot and cold at the same time. There was a heat coming from my bones...It's hot, almost like there's a fire burning in your bones. And then, they turn black...The rubbing together causes pain, it causes that heat and causes the bones to be shapeless.
- Shows some basic understanding of RA.
- Taking medication has become routine but before, the pain reminded her. Now she takes it even without feeling the pain so that she can prevent it.
- Side effects: headaches- takes spectrapaine, ulcers-takes omeprazole.
- Seems to equate taking meds with looking after herself...No, they don't upset me because I think if I get upset at them, then it means I don't care for my life. She feels this way even though she has a problem with relying on medication on a daily basis.
- Impact on her life...I feel small. I'm no longer brave. Everything about me has gone down...My life, in general, has not been improved but the pains have been reduced.
- Expresses dissatisfaction about the service at the pharmacy but understands that the working conditions may not be easy for the

pharmacists and that they are trying their best...Those people (pharmacists) work. There are a lot of us [patients]. They work. Even if they get annoyed, they're people. They work.

### **P20-Smoking**

- Takes meds as prescribed and has some understanding of the reasons why.
- Refers to RA as an infection but has some understanding of it.
- All her joints were affected. She was taking OTC medication until they could no longer control the pain.
- Seems to believe that it first manifested while she was a smoker but she ignored the signs.
- Expresses that the school has been very helpful and has help to refresh things in her mind about RA.
- MTX was out of stock for 2 months so she went without... And then for these 2 months, I didn't get Methotrexate. Ya, and then my health wasn't very good. Very bad...They didn't have it at the chemist. And I thought of going to the pharmacy to buy but I didn't know I need to go with a script and then they will help you. But it was bad these 2 months.
- Takes meds because they make her feel better and to prevent pain. Makes reference to how bad life was before she had the correct meds.
- Says she finds it easy to communicate with the Drs and nurses. They have been very helpful... I remembered now to ask [the Dr] but it was just one of the things. She explained it's part of the arthritis...Most of the time, [they] are very helpful. Really they are helpful. Could it be easier because there isn't a language barrier?
- Pharmacy issue- the biggest issue is the amount of time she has to wait there. Pays somebody to collect her medication for her...The pharmacy? It's a bad experience. [We] sit there a very long time, really. Every time, I don't usually go there and then I send someone. I pay someone to come and fetch my medication for me. Uh, the pharmacy, they need to do something about that place. Why can't they keep our medication here [at the clinic]?



**APPENDIX E: HOSPITAL PERMISSION TO CONDUCT RESEARCH**

**MEDICAL ADVISORY COMMITTEE  
CHRIS HANI BARAGWANATH HOSPITAL  
PERMISSION TO CONDUCT RESEARCH**

Date: 06 December 2011

UNIVERSITY: Witwatersrand

Principal Investigator Boitshoko Kobue

Department: Pharmacology

Supervisor (If relevant):.

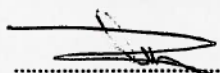
Permission Head Department (where research conducted) Not yet

Date of start of proposed study: January 2012

Date of completion of data collection April 2012

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

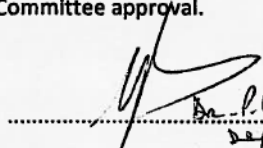
- You obtain permission from the Head of the Division of Rheumatology at Chris Hani Baragwanath Hospital
- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

  
.....

Recommended

(On behalf of the MAC)

Date: 06 December 2011

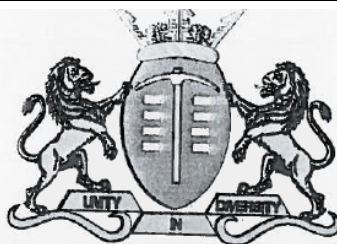
  
.....  
Dr. P. L. ...  
DEP CEO

Approved/Not Approved

Hospital Management

Date: 12/12/2011

**APPENDIX F: CLINIC PERMISSION TO CONDUCT RESEARCH**



**health and  
social development**

**Department: Health and Social Development  
GAUTENG PROVINCE**

Prof M. Tikly  
Department of Medicine

Tele: 011 933 9377

Fax: 011 938 8738

12 March 2012

To whom it may concern

I, Mohammed Tikly, in my capacity as Head of Rheumatology at Chris Hani Baragwanath Academic Hospital consent Ms Boitshoko Kobue to conduct her MSc research project entitled "Factors affecting medication adherence in Rheumatoid Arthritis" at the Arthritis clinic, Chris Hani Baragwanath Academic Hospital. She can commence as soon as she has approval of her research from her relevant hospital and University authorities.

Regards

Prof M Tikly

Head: Department of Rheumatology

Chris Hani Baragwanath Academic Hospital

## APPENDIX G: ETHICS APPROVAL CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG  
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)  
R14/49 Miss Boitshoko Kobue

CLEARANCE CERTIFICATE M110718

PROJECT Factors Affecting Concordance in Patients Recently Diagnosed with Chronic Conditions

INVESTIGATORS Miss Boitshoko Kobue.

DEPARTMENT Department of Pharmacy & Pharmacology

DATE CONSIDERED 29/07/2011

M110718DECISION OF THE COMMITTEE\* Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 01/12/2011 CHAIRPERSON   
(Professor PE Cleaton-Jones)

\*Guidelines for written 'informed consent' attached where applicable  
cc: Supervisor : Ms Shirra Moch

-----  
DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

## APPENDIX H: CHANGE OF TITLE APPROVAL



Faculty of Health Sciences  
Medical School, 7 York Road, Parktown, 2193  
Fax: (011) 717-2119  
Tel: (011)717-2075/6

Reference: Ms Salamina Segole  
E-mail: Salamina.segole@wits.ac.za  
12 April 2012  
Person No: 0703122D  
PAG

Miss BO Kobue  
1799 Macaulay Crescent  
Mondeor Extension 3  
Johannesburg  
2091

South Africa

Dear Miss Kobue

### **Master of Science in Medicine: Approval of Title**

We have pleasure in advising that your proposal entitled "*Factors affecting medication adherence in rheumatoid arthritis*" has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'S Benn', with a horizontal line underneath.

Mrs Sandra Benn  
Faculty Registrar  
Faculty of Health Sciences

## **APPENDIX I: EXCERPT FROM GENERAL ETHICAL GUIDELINES FOR HEALTH RESEARCHERS (HEALTH PROFESSIONALS COUNCIL OF SOUTH AFRICA)**

11

### **11. DUTIES TO ANIMALS**

Health researchers should:

- 11.1 Accept responsibility for the care of animals used in health research and respect their welfare.
- 11.2 Demonstrate that their research is justifiable and scientifically based on literature reviews, prior observations, approved studies and, when applicable, laboratory and animal studies.
- 11.3 Follow the ethical and regulatory guidelines established at institutional level regarding the use of animals by professional associations, and by governmental authorities.
- 11.4 Use, when appropriate, inanimate materials and processes instead of animals.
- 11.5 When the use of an animal species is scientifically necessary, use lower animal species that may be less susceptible to pain and suffering - without compromising the integrity of the research.
- 11.6 When designing the research protocol, use the minimum number of animals necessary to yield valid answers to the research hypothesis.
- 11.7 Take active measures to use procedures that minimise both the incidence and severity of the pain and suffering experienced by animals.

### **12. DUTIES TO THE ENVIRONMENT**

Health researchers should:

- 12.1.1 Ensure that the research does not impact on the environment in a manner that is harmful to the health and well-being of the population, nature and the environment. In all instances health researchers must ensure that the environment is protected for the benefit of present and future generations as is required by the South African Constitution.
- 12.1.2 Recognise that natural resources are limited and guard against their exploitation.
- 12.1.3 Health researchers should protect the environment and the public by assuring that health care waste is disposed off legally and in an environmentally friendly manner

### **13. DATA AND SPECIMEN STORAGE**

- 13.1 Data and specimens obtained as a result of research activity should be securely stored.
  - 13.2 Data, including tape recordings should be stored for a minimum of 2 years after publication or 6 years in the absence of publication.
  - 13.3 There must be justifiable reasons which should be provided to Research Ethics Committees for data and specimens to leave the country. This should only be done after a Material Transfer Agreement has been signed and submitted to the local Research Ethics Committee.
-

## APPENDIX J: DRUG INFORMATION SHEETS USED IN THE STUDY

### CHLOROQUINE (NIVAQUINE)

#### DISCRIPTION

200mg Chloroquine sulphae-150mg chloroquine: white biconvex tablet.

#### DOSAGE

The exact dose will be specified by the prescribing doctor.

150-300mg daily initially, reduced to 150mg after 7-10days. After remission is obtained, a 5-days-a-week regimen should be attempted. Recommended dose 2,4mg/kg.

#### WHAT DOES IT DO?

Chloroquine contributes to a reduction in the inflammation in the joints associated with RA. It will take a month or two for the stiffness and pain to get better.

#### SIDE-EFFECTS

COMMON	RARE
GIT effects, rashes, headache, dizziness, blurred vision	Ototoxicity, blood dyscrasias, cardiovascular effects, neuropsychiatric effects.

- It is very important that the Dr be alerted should the patient experience any side effects.
- Regular blood tests should be conducted, along with careful patient monitoring.
- It is very important to have eye tests and to wear sunglasses when out during daytime.

#### DRUG INTERACTIONS

Antacids (magnesium trisilicate, kaolin): Absorption of chloroquine may be reduced.

Cimetidine: Metabolism and elimination of chloroquine may be reduced.

Co-trimoxazole and other sulphonamides: Increased risk of potentially fatal skin reactions.

Mefloquine: Increased risk of neurotoxicity and cardiotoxicity.

## LEFLUNOMIDE (ARAVA)

### DESCRIPTION

10mg: white to almost white, round-film coated tablets with a diameter of 7mm. Embossment: ZBN

20mg: yellowish to ochre, spherical, triangular film-coated tablet with a height of 7mm. Embossment: ZBO

### DOSAGE

10-20mg daily; will be specified by prescribing doctor.

### WHAT DOES IT DO?

Arava belongs to a class of drugs known as the Disease Modifying Anti-Rheumatic Agents (DMARDs). It helps to reduce the joint inflammation and pain associated with RA. The effects, however, will only start showing after a few months.

### SIDE-EFFECTS

COMMON	UNCOMMON	RARE
Diarrhea, nausea, vomiting, abdominal pain, weight loss, mouth ulcers, headache, dizziness, rashes, hair loss.	Anaemia, thrombocytopenia, urticaria, raised potassium levels	Hepatitis, agranulocytosis, anaphylaxis, toxic epidermal necrolysis, Stevens-Johnson Syndrome

- It is very important that the Dr be alerted should the patient experience any side effects.
- Regular blood tests should be conducted, along with careful patient monitoring.

### CAUTIONS

Pregnant or lactating women should not use Arava. It has been found to be harmful to the baby. If patients are planning to fall pregnant, they have to stop using Arava for at least 3 months before they start trying. Men also need to use family planning. CONSULT WITH THE DOCTOR

## SALPHASALAZINE (SALAZOPYRIN)

### DESCRIPTION

500mg: Yellow-orange, elliptical, convex, film coated tablet with "KPh" on the one side and "102" on the other.

### DOSAGE

The exact dose will be specified by the prescribing doctor.

500mg daily after food. May be increased by 500mg/day at weekly intervals until the maximum point of 4 tablets daily (2g)- 2tablets bd.

### WHAT DOES IT DO?

Salazopyrin helps to reduce the pain and inflammation at the joints. These effects, however, will only start to show after 2 -3 months. If the pain and stiffness do not get better after 6 months, the Dr must be notified and treatment with Salazopyrin may be stopped.

### SIDE-EFFECTS

COMMON	UNCOMMON	RARE
Headache, fever, loss of appetite, leucopenia, NVD, rashes, orange discolouration of urine	Dizziness, anaemia, ringing of the ears, pseudomonas colitis, joint pain, pancreatitis, depression, shortness of breath, coughing, photosensitivity, hair loss, kidney damage	SLE, hypoglycaemic effects, hypothyroidism

- It is very important that the Dr be alerted should the patient experience any side effects.
- Regular blood tests should be conducted, along with careful patient monitoring.

### DRUG INTERACTIONS

Digoxin and folate: Absorption of Salazopyrin is reduced

Iron: chelation occurs and absorption is hampered.

Methotrexate and Phenytoin: their effects may be potentiated

Sulphonylureas: hypoglycaemic effects may be enhanced

Digoxin: potentiation of anticoagulation



# METHOTREXATE

## DESCRIPTION

2,5mg: flat-faced, yellow tablet, bevel edged and scored with a diameter of 6,5mm. Coded MXT1/2 on one side and PCH on the other side.

## DOSAGE

The exact dose will be specified by the prescribing doctor.

7,5mg weekly (as a single dose or 2,5mg 12 hourly for 3 doses), adjusted according to response, maximum 25mg per week.

## WHAT DOES IT DO?

Methotrexate helps to reduce the joint inflammation and swelling associated with RA. These effects, however, will only start to show after a month or 2.

## SIDE-EFFECTS

COMMON	UNCOMMON
Mouth ulceration and bleeding, skin rashes, headache, drowsiness, blurred vision,	Interstitial pneumonitis, bone marrow suppression, kidney and liver damage

- It is very important that the Dr be alerted should the patient experience any side effects.
- Regular blood tests should be conducted, along with careful patient monitoring.
- Alcohol must be avoided to prevent further damage to the liver.

## DRUG INTERACTIONS

Probenecid, aspirin and other NSAIDs: inhibit renal clearance of Methotrexate, increasing toxicity risk.

Phenytoin, Trimethoprim, co-trimoxazole and triamterene: additive ant-folate activity, increased risk of Methotrexate toxicity.

Alcohol: enhances hepatotoxicity.

Allopurinol: dose may need to be increased as Methotrexate may increase serum uric acid concentrations.

Anticoagulants: Methotrexate may inhibit clotting factor synthesis; monitor INR closely.

Live virus vaccines: should be avoided due to immunosuppression.

**APPENDIX K: INFORMED CONSENT FORM TO PARTICIPATE IN THE STUDY**



Informed Consent Form  
Factors affecting adherence in patients diagnosed with  
Rheumatoid Arthritis

Division of Pharmacology  
University of the Witwatersrand

I \_\_\_\_\_ (insert name of subject) aged \_\_\_\_\_ years, consent to participate in the study on adherence in Rheumatoid Arthritis.

Miss Kobue has fully explained the questionnaire and its purpose, and I understand and appreciate:

- a) That by answering the questions I am helping to further knowledge on factors affecting adherence in patients diagnosed with RA in South Africa;
- b) There is no financial benefit attached to participation in this survey.

I also appreciate that I can stop participating in the study at any time.

\_\_\_\_\_ (signature of participant)

I Miss Kobue declare that I have explained the purpose of the adherence survey to the participant. In addition, I have indicated that if the participant requires further information or assistance with their prescribed medication they can contact the clinic sister or the relevant pharmacist at the clinic. The participant has been informed that there is no financial benefit attached to participation in this survey.

I believe my explanation to have been fully understood by the consenting party.

\_\_\_\_\_ (signature of administrator)

**APPENDIX L: CONSENT FORM TO BE VIDEO TAPED**



Informed Consent Form  
Factors affecting adherence in patients diagnosed with  
Rheumatoid Arthritis

Division of Pharmacology

University of the Witwatersrand

I \_\_\_\_\_ (insert name of subject) aged \_\_\_\_\_ years, consent to being video-taped for the study on adherence in Rheumatoid Arthritis (RA) when I talk with the researcher.

Miss Kobue has explained the purpose the video-taping and I understand and appreciate that:

- a) I am being video taped because the researcher needs to get a good set of data during the interviews so that the transcripts will be accurate and adequately reflect what was said in the interview. The video-tapes will be used as visual evidence of how I take my medication.
- b) The recording will be handled with the strictest of confidentiality and will be kept in a locked cupboard. The video will not be shown to anyone except the researcher and her supervisors.

\_\_\_\_\_ (signature of participant)

I Miss Kobue declare that I have explained the purpose of video taping the responses for the adherence survey to the participant. In addition, I have indicated that the recording will be handled with the strictest of confidentiality. The participant has been informed that there is no financial benefit attached to participation in this survey.

I believe my explanation to have been fully understood by the consenting party.

\_\_\_\_\_ (signature of administrator)

## APPENDIX M: PAIN ASSESSMENT SCALES



### Pain Assessment Scales

The National Initiative on Pain Control™ (NIPC™) has provided these diagnostic tools to assist you in assessing the severity and quality of pain experienced by your patients. We suggest that you produce multiple photocopies so that you may obtain written feedback to place in the patient's history file.

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### Wong-Baker FACES Pain Rating Scale



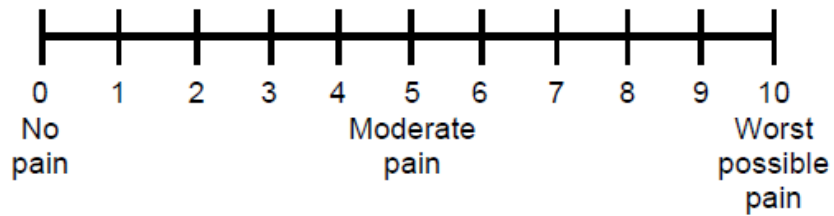
Explain to the person that each face is for a person who feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. Face 0 is very happy because he doesn't hurt at all. Face 1 hurts just a little bit. Face 2 hurts a little more. Face 3 hurts even more. Face 4 hurts a whole lot. Face 5 hurts as much as you can imagine, although you don't have to be crying to feel this bad. Ask the person to choose the face that best describes how he is feeling.

Rating scale is recommended for persons age 3 years and older.

**Brief word instructions:** Point to each face using the words to describe the pain intensity. Ask the child to choose face that best describes own pain and record the appropriate number.

From Wong DL, Hockenberry-Eaton M, Wilson D, Winkelstein ML, Schwartz P: *Wong's Essentials of Pediatric Nursing*, 6/e, St. Louis, 2001, P. 1301. Copyrighted by Mosby, Inc. Reprinted by permission.

## 0–10 Numeric Pain Rating Scale

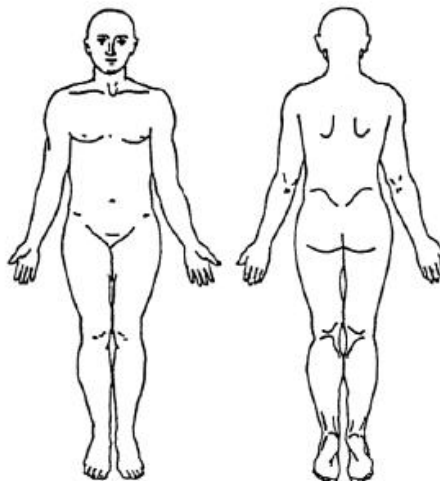


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## Where is Your Pain?

Please mark, on the drawings below, the areas where you feel pain. Write "E" if external or "I" if internal near the areas which you mark. Write "EI" if both external and internal.



Reprinted from *Pain*, Vol 1, Melzack R, The McGill Pain Questionnaire: major properties and scoring methods, 277-299, Copyright 1975, with permission from the *International Association for the Study of Pain*.

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PAIN QUALITY ASSESSMENT SCALE<sup>©</sup> (PQAS<sup>©</sup>)

**Instructions:** There are different aspects and types of pain that patients experience and that we are interested in measuring. Pain can feel sharp, hot, cold, dull, and achy. Some pains may feel like they are very superficial (at skin-level), or they may feel like they are from deep inside your body. Pain can be described as unpleasant and also can have different time qualities.

The Pain Quality Assessment Scale helps us measure these and other different aspects of your pain. For one patient, a pain might feel extremely hot and burning, but not at all dull, while another patient may not experience any burning pain, but feel like their pain is very dull and achy. Therefore, we expect you to rate very high on some of the scales below and very low on others.

Please use the 20 rating scales below to rate how much of each different pain quality and type you may or may not have felt OVER THE PAST WEEK, ON AVERAGE.

1. Please use the scale below to tell us how <b>intense</b> your pain has been over the past week, on average.		
No pain	0   1   2   3   4   5   6   7   8   9   10	The most <b>intense</b> pain sensation imaginable
2. Please use the scale below to tell us how <b>sharp</b> your pain has felt over the past week. Words used to describe sharp feelings include "like a knife," "like a spike," or "piercing."		
Not sharp	0   1   2   3   4   5   6   7   8   9   10	The most <b>sharp</b> sensation imaginable ("like a knife")
3. Please use the scale below to tell us how <b>hot</b> your pain has felt over the past week. Words used to describe very hot pain include "burning" and "on fire."		
Not hot	0   1   2   3   4   5   6   7   8   9   10	The most <b>hot</b> sensation imaginable ("burning")

4. Please use the scale below to tell us how <b>dull</b> your pain has felt over the past week.		
Not dull	0   1   2   3   4   5   6   7   8   9   10	The most <b>dull</b> sensation imaginable
5. Please use the scale below to tell us how <b>cold</b> your pain has felt over the past week. Words used to describe very cold pain include "like ice" and "freezing."		
Not cold	0   1   2   3   4   5   6   7   8   9   10	The most <b>cold</b> sensation imaginable ("freezing")
6. Please use the scale below to tell us how <b>sensitive</b> your skin has been to light touch or clothing rubbing against it over the past week. Words used to describe sensitive skin include "like sunburned skin" and "raw skin."		
Not sensitive	0   1   2   3   4   5   6   7   8   9   10	The most <b>sensitive</b> sensation imaginable ("raw skin")
7. Please use the scale below to tell us how <b>tender</b> your pain is when something has pressed against it over the past week. Another word used to describe tender pain is "like a bruise."		
Not tender	0   1   2   3   4   5   6   7   8   9   10	The most <b>tender</b> sensation imaginable ("like a bruise")
8. Please use the scale below to tell us how <b>itchy</b> your pain has felt over the past week. Words used to describe itchy pain include "like poison ivy" and "like a mosquito bite."		
Not itchy	0   1   2   3   4   5   6   7   8   9   10	The most <b>itchy</b> sensation imaginable ("like poison ivy")
9. Please use the scale below to tell us how much your pain has felt like it has been <b>shooting</b> over the past week. Another word used to describe shooting pain is "zapping."		
Not shooting	0   1   2   3   4   5   6   7   8   9   10	The most <b>shooting</b> sensation imaginable ("zapping")

10. Please use the scale below to tell us how <b>numb</b> your pain has felt over the past week. A phrase that can be used to describe numb pain is "like it is <u>asleep</u> ."
Not numb <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>numb</b> sensation imaginable ("asleep")
11. Please use the scale below to tell us how much your pain sensations have felt <b>electrical</b> over the past week. Words used to describe electrical pain include " <u>shocks</u> ," " <u>lightning</u> ," and " <u>sparking</u> ."
Not electrical <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>electrical</b> sensation imaginable ("shocks")
12. Please use the scale below to tell us how <b>tingling</b> your pain has felt over the past week. Words used to describe tingling pain include " <u>like pins and needles</u> " and " <u>prickling</u> ."
Not tingling <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>tingling</b> sensation imaginable ("pins and needles")
13. Please use the scale below to tell us how <b>cramping</b> your pain has felt over the past week. Words used to describe cramping pain include " <u>squeezing</u> " and " <u>tight</u> ."
Not cramping <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>cramping</b> sensation imaginable ("squeezing")
14. Please use the scale below to tell us how <b>radiating</b> your pain has felt over the past week. Another word used to describe radiating pain is " <u>spreading</u> ."
Not radiating <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>radiating</b> sensation imaginable ("spreading")
15. Please use the scale below to tell us how <b>throbbing</b> your pain has felt over the past week. Another word used to describe throbbing pain is " <u>pounding</u> ."
Not throbbing <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>throbbing</b> sensation imaginable ("pounding")

16. Please use the scale below to tell us how <b>aching</b> your pain has felt over the past week. Another word used to describe aching pain is " <u>like a toothache</u> ."
Not aching <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>aching</b> sensation imaginable ("like a toothache")
17. Please use the scale below to tell us how <b>heavy</b> your pain has felt over the past week. Other words used to describe heavy pain are " <u>pressure</u> " and " <u>weighted down</u> ."
Not heavy <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>heavy</b> sensation imaginable ("weighted down")
18. Now that you have told us the different types of pain sensations you have felt, we want you to tell us overall how <b>unpleasant</b> your pain has been to you over the past week. Words used to describe very unpleasant pain include " <u>annoying</u> ," " <u>bothersome</u> ," " <u>miserable</u> ," and " <u>intolerable</u> ." Remember, pain can have a low intensity but still feel extremely unpleasant, and some kinds of pain can have a high intensity but be very tolerable. With this scale, please tell us how <b>unpleasant</b> your pain feels.
Not unpleasant <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>unpleasant</b> sensation imaginable ("intolerable")
19. We want you to give us an estimate of the severity of your <b>deep</b> versus <b>surface</b> pain over the past week. We want you to rate each location of pain separately. We realize that it can be difficult to make these estimates, and most likely it will be a "best guess," but please give us your best estimate.
<b>HOW INTENSE IS YOUR DEEP PAIN?</b>
No <b>deep</b> pain <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>intense deep</b> pain sensation imaginable
<b>HOW INTENSE IS YOUR SURFACE PAIN?</b>
No <b>surface</b> pain <input type="text" value="0"/> <input type="text" value="1"/> <input type="text" value="2"/> <input type="text" value="3"/> <input type="text" value="4"/> <input type="text" value="5"/> <input type="text" value="6"/> <input type="text" value="7"/> <input type="text" value="8"/> <input type="text" value="9"/> <input type="text" value="10"/> The most <b>intense surface</b> pain sensation imaginable

20. Pain can also have different time qualities. For some people, the pain comes and goes and so they have some moments that are completely without pain; in other words the pain "comes and goes". This is called **intermittent** pain. Others are never pain free, but their pain types and pain severity can vary from one moment to the next. This is called **variable** pain. For these people, the increases can be severe, so that they feel they have moments of very intense pain ("breakthrough" pain), but at other times they can feel lower levels of pain ("background" pain). Still, they are never pain free. Other people have pain that really does not change that much from one moment to another. This is called **stable** pain. Which of these best describes the time pattern of your pain (please select only one):

- I have **intermittent** pain (I feel pain sometimes but I am pain-free at other times).
- I have **variable** pain ("background" pain all the time, but also moments of more pain, or even severe "breakthrough pain or varying types of pain).
- I have **stable** pain (constant pain that does not change very much from one moment to another, and no pain-free periods).

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