

ILLNESS NARRATIVES AND COVID-19

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Abstract

This research is an autoethnographically grounded study that examined eleven illness narratives on COVID-19 from a white middle to upper class sample within South Africa. The study examined how individuals within this group conceptualised, reacted to and were affected by COVID-19. This is done through the examination of various aspects of the illness narratives presented, namely, diagnosis, help-seeking behaviour, treatment, service utilisation and modes of reasoning for COVID-19. The study makes several interlinked arguments for understanding COVID-19 illness, such as the distinction between disease (as a biomedical construct) and illness (as a subjective experience), the influence of social networks, resources and class on individual suffering, that inequalities in healthcare shape the capacity of people to suffer, and the failure of statistical representations in acknowledging individual suffering. Although participants within the study had access to medical aid and adequate funding for healthcare provisions it is illustrated that social relationships were critical resources for coping with the various uncertainties surrounding COVID-19. Finally, the report indicates that the uncertain nature of COVID-19 is a prominent feature within the illness narratives examined which suggests a greater temporality for the adverse effects of COVID-19 than would be expected within its biomedical categories.

Introduction

The COVID-19 pandemic has had a multifaceted impact on all aspects of society. The attention that is given to the severity of this disease varies between individuals over time due to various temporal factors (i.e., infection rates, vaccination progress, hospital recovery rates, etc). Acknowledgement of COVID-19's adverse impact is unavoidable when an individual is forced to experience the virus first-hand. Hence, the purpose of this research report was to gain a better empirical and theoretical understanding of how individuals understood and assigned meaning to their experience of COVID-19. The primary focus of this research report was to investigate the question 'What understanding do illness narratives offer for the experience of COVID-19 and its effects on the individual?'. This aimed to assist in broadening the understanding of both the personal and social impact of the pandemic within South Africa. The question was examined through the analysis of autobiographical accounts of those who experienced COVID-19 during the latter half of 2021. The research was conducted amongst a majority white population all in the middle to the upper class. This offered insight into a presumably homogenous group that was afforded more comfortability during the period of COVID-19 given the groups' ties to systemic factors and resource acquisition. This insight questions the generalization of the COVID-19 experience by examining how COVID-19 was experienced by those who were presumed to have more comfortability over the COVID-19 period. Data collection and analysis was guided by the McGill Illness Narrative Interview (MINI) (Groleau et al., 2006). Analysis of interviews focused on identifying stigmatization, illness metaphors, and idioms of distress as a means of better contextualising the effects of the COVID-19 illness experience. The researcher had contracted COVID-19 before commencing this research report and my experience is offered in an autoethnographic manner to offer a more nuanced, self-reflexive, and complementary discussion of the illness narratives researched.

My COVID-19 Experience

My experience of having COVID-19 occurred during the second wave of infections in South Africa which was around the middle of December 2020. There was a general heightened sense of worry and anxiety due to the increased incidence of COVID-19 infections that reflected despotism because of the failure to see improvements towards ending the COVID-19 pandemic. The first inclination that I may have

contracted the virus occurred during the night of the 20th of December 2020, as I couldn't sleep due to a general feeling of unease that engulfed my body. The only way I can describe the feeling of that uneasiness is that of night sweats, except without the sweating. I remember feeling a heightened sense of worry as I had never had this experience before, which made me suspect that I may have caught the virus. This suspicion only grew as I woke after having finally managed to fall asleep in the early hours of the morning as it appeared that I had phlegm in my throat and had developed a cough. I was able to book a doctor's appointment even though many healthcare facilities were fully booked during this period. I recount feeling a sense of being lucky to be able to book the appointment with such relative ease. However, on reflection, I recognise that this had little to do with luck but rather the privileged class position in which I am situated which provided me with medical aid and a doctors' room that had the means of establishing outside COVID-19 examination tents.

When going to the doctor's rooms I remember the protocols and procedures being completely alien, such as having to stand in the parking lot, having no human contact before consultation, and seeing my doctor in Personal Protective Equipment (PPE). After an examination by the doctor, he believed that I most likely didn't have COVID-19 but suggested that I should still get tested for peace of mind. There was a testing station close to where I live that was able to give results on the same day of testing (another indication of my privileged position). It came as quite a shock when I received the positive COVID-19 test result. Of great recourse in dealing with the panic of receiving a positive result was the advice of various family members and friends.

The advice followed similar instructions given by various formal and informal media sources, such as taking vitamins, immune boosters and getting plenty of rest. Of great comfort was the stories that these individuals told me of others who had the virus, what they did, and the advice they had received from experts they knew personally.

Fortunately, at the time I was house sitting for someone in my local area, so isolation was not an issue. The doctor arranged a script for medication, which could be dropped off by a family member. The physical symptoms that I experienced during the next week ranged from extreme fatigue, difficulty breathing, coughing, sinus, diarrhoea, vomiting, and rash on my left hand. The only two constants throughout this time was fatigue and difficulty breathing which worsened around the third or fourth day after receiving the positive result. The other symptoms were more erratic, appearing one day and gone the next. In terms of treatment, I took vitamins over the fourteen days of isolation and had been given an asthma pump and nasal spray to use when necessary. On about day three or four, my doctor prescribed a course of cortisone, and from what I understand, a more intense asthma pump due to my doctor's concern of my condition worsening which in hindsight was probably justified given my increased anxiety about going to hospital due to the uncertainty of what the next day could bring. Thankfully, after about day ten I had recovered from COVID-19 and since have not experienced any severe long term COVID-19 effects. If I look back on my experience, I think that I may have had a bit of 'brain fog' and struggled to concentrate for a few weeks after.

My experience of COVID-19 was difficult to comprehend given how the virus affected those around me so differently. Those around me were able to illustrate different experiences, perspectives, and beliefs that influenced my reflections on my experience of COVID-19. One important aspect of my reflections was the social nature of COVID-19, that social contexts played a vital role in how I was able to respond and comprehend my infection. It was apparent that the COVID-19 experience is social in nature and I wanted to investigate how the social world impacted this experience.

The Problem Statement

There are numerous social, environmental, and individual factors influencing the experience of COVID-19. Structural vulnerabilities (Team & Manderson, 2020), as well as long-standing systematic and social inequalities (CDC, 2021a), have frequently been highlighted over the course of the pandemic. These various vulnerabilities and inequalities that often intersect with race, class, and gender within South Africa, are at increased risk of becoming ever-more prevalent due to the economic impact of COVID-19 lockdown restrictions and regulations. Other socio-environmental factors impacted by COVID-19 regulations include both religion (Wildman et al., 2020), and culture (Airhihenbuwa et al., 2020) which can play important roles in how individuals understand and assign meaning to their illness. The onset of COVID-19 can potentially be mild or life-threatening, its side effects can be potentially known or contested, and its duration is short or relatively long-term in the face of recent evidence for ‘long covid’ (Ladds et al., 2020; Sudre et al., 2021). The problem of gaining an understanding of the effects of COVID-19 is the novelty and sheer variability of its effects. The uncertainty around COVID-19 is also heightened due to the proliferation of information that is often contradictory and rapidly evolving. The virus itself is changing with various variants. The virus runs alongside “an epidemic of fear, suspicion and stigmatisation; an epidemic of interpretation, explanation and moralisation; and an epidemic of proposals and action” (Staniland & Smith, 2013, p. 321). People who contract the virus experience heightened uncertainty and are often uncertain how the virus has affected them. Illness narratives serve not only for the individual to make sense of their experience of illness but also allow the researcher to make sense of what is happening. Illness narratives examine the meaning that individuals assign to their experience of illness, following a constructivism framework (Groleau et al., 2006) that values the subjectivity of illness (Conrad & Barker, 2010). Illness narratives will therefore be used within this paper to gain an understanding of the COVID-19 illness experience.

Rationale

As stipulated within the problem statement, the COVID-19 pandemic has had a great propensity to further exacerbate structural vulnerabilities or the traditional fault lines of society. This is not a new phenomenon as inequalities have greatly impacted health outcomes, particularly within South Africa and its historical ancestries of apartheid (Manderson & Levine,

2018). However, Nolwazi Mkhawnazi illustrates the dangers of illustrating ‘a single story’ or dominant narrative of inequality and its reciprocal relationship to health outcomes and wellbeing as other aspects of the story can be neglected (Manderson & Levine, 2018; 2016). The rationale of this research project is based on investigating the homogeneity of the COVID-19 illness experience. That the subjective experience and impact of having to contend with COVID-19 infection differs greatly even among presumably homogenous groups such as race, class, etc. This can distort and impede a more nuanced comprehension of how COVID-19 affects individuals. Given that the sample consists of individuals from a middle-to-upper class with most of these individuals being of a white racial group, it would be expected that these individuals would be better equipped to deal with the impact of the COVID-19 pandemic. This is an area of enquiry rather than a synthesis of race and class and can add to areas such as critical whiteness studies (CSW) by illustrating for example instances of white privilege. However, the principal aim of this research report is to examine the precarity and subjectivity of experiencing COVID-19 and the subsequent assumptions, generalizations, and polarisations that distort a more concrete understanding of COVID-19. In this sense, the rationale of this research paper is to add ‘other’ stories to the dominant narratives of COVID-19 that may push research in different directions empirically and theoretically. Particularly, a story that relays that the illness experience of the virus varies greatly and its effects on the individual and social context are not adequately understood and need to be investigated.

Literature Review

This literature review discusses the concepts of illness experiences and illness narratives to provide a comprehensive framework of enquiry into the illness experience of COVID-19. The review looks at the emergence of the concept of illness experience, the use of narratives as a tool to unpack the illness experience, including the use of metaphors, stigmas, and idioms of distress as tools to unpack the illness experiences and various facets of how individuals experience COVID-19.

South African Context

A prominent feature of South African history that has influenced disease epidemiology and healthcare was industrialisation and urbanisation. These both were significantly influenced by the discovery of diamonds in Kimberly during 1867 and the discovery of gold on the

Witwatersrand around 1884 (Kark, 2003). These discoveries fast-tracked the establishment of the migrant labour system or the “movement of millions of young men via South Africa’s well-developed transport network” (Phillips, 2001, p. 13) which has the detrimental consequence of being “critical to the introduction and spread of communicable disease to and in the country” (Phillips, 2001, p. 13). The migrant labour system perpetuated poor health outcomes for Black Africans (Marks, 2002) a characteristic that was further reinforced by apartheid. The apartheid regime within South Africa was a fundamental feature that shaped its “epidemiology of disease, demographic structure, and health systems and services... derived from scientific hierarchies and structures that governed different ‘groups’...” (Manderson & Levine, 2018, p. 566). These social disadvantages continue post-apartheid and are even more nuanced in a globalising world where South Africa is a middle-income country. Myer et al (2004) illustrate that social disadvantage within South Africa is linked to poor health outcomes. However, the influence of poverty on health is not simply understood as “the relations between social stratification and health are far more complex than a simple, monotonic gradient” (Myer et al., 2004, p. 114). South Africa is also experiencing a ‘bipolar’ epidemiological transition, where both non-communicable diseases (such as cancer, heart disease, etc) and infectious diseases (such as HIV/AIDS, tuberculosis, etc) are deemed to be increasing having a complex interplaying with social stratification and social contexts (Myer et al., 2004). South Africa’s disease aetiology and relationship to structural, historical, political, and socio-economic factors were already complex before the arrival of the COVID-19 pandemic. COVID-19 further catalysed the complexification of these relationships.

One aspect of this complexity is systematic inequalities faced by those within South Africa. Carolin et al indicate that even though apartheid has ended, and new democratic political ideologies have been introduced, post-apartheid whiteness perpetuates systems of privilege - “Post-apartheid whiteness is a set of complex discursive positionings, tied to apartheid’s white supremacist ideologies yet refracted through the diffuse ideological, political and cultural forces that characterise the present. Although the distribution of formal political power strongly suggests a shift towards a non-racial national context, the legacy of the country’s racialisation is imbricated into all aspects of social and cultural life. Whiteness remains enmeshed in normative practices of power and rooted in material conditions of inequality and ongoing relations of social injustice” (2020, p. 1). Race is intrinsically intertwined in health outcomes within South Africa. Therefore, any study on COVID-19 needs to intrinsically highlight this facet of society. One way of doing this is through the use of critical whiteness studies (CSW) which aims to identify invisible norms and make whiteness visible to

understand how ‘difference’ within society is created and maintained through systems of dominant power (Applebaum, 2016). Therefore, both class and race play a vital role in how one experiences COVID-19 as they both influence the resources that an individual has access to cope and defend themselves against adverse effects of the disease itself as well as political, economic, and social hardships presented due to the pandemic.

Contextualising White Middle and Upper Class Healthcare in South Africa

To adequately contextualise those interviewed within this research it must be acknowledged that there are a variety of determinants that shape white middle-class life in particular relation to health outcomes. South Africa is characterised as one of the most unequal countries in the world as it was estimated in 2017 that 55% of its population fell under the ‘Upper Bound Poverty Line’ (Broadbent et al., 2020). The most apparent feature shaping white middle-class healthcare is being on the favourable side of South Africa’s ‘two-tiered healthcare system’ (Young, 2016), in other words, the ability to access private healthcare. In South Africa, approximately 30% of doctors work in the public healthcare sector serving about 40 million people or 84 % of the population, while the other 70% of doctors work within the private healthcare sector administering healthcare to the remaining 16% (roughly 8 million people) of individuals who can afford medical aid or health insurance (Mayosi & Benatar, 2014). Young (2016) illustrates that there is a major gap between public and private healthcare, public healthcare is characterised by a lack of adequate care, extensive waiting times, hurried consultations, run-down facilities and lack of adequate disease control and preventative procedures, while private healthcare is the opposite with regards to all of these aspects. Therefore, it is imperative to note that this research report and its narratives examined bring to the fore the experience of an unknown sense of risk, insecurity and uncertainty that accompanied the COVID-19 pandemic against the background of an otherwise relatively secure form of living and earning.

COVID-19

Coronavirus Disease 2019 (COVID-19) is classified as a respiratory disease that is caused by a novel coronavirus that quite closely resembles that of severe acute respiratory syndrome (SARS), with the first cases being identified in the Chinese city of Wuhan, in December 2019 (Fauci et al., 2020). The World Health Organisation declared COVID-19 a pandemic on the 11th of March 2020 as the virus spread to various countries around the world (Isba et al., 2020). On the 5th of March 2020, the South African Department of Health verified the first case of

COVID-19 within the country (Mkhize, 2020) and since then has experienced four waves of COVID-19 infections. The first wave occurred around June to August 2020, the second from November 2020 to January 2021, the third taking place around May to September of 2021, and the fourth and most recent wave starting in November and ending in December of 2021 (Maslo et al., 2022). COVID-19 has been metaphorized as coming in waves reflecting the “ebbs and flows in the epidemiological progression of the disease, multi-factored to account for changes in seasons, medical treatments and ineffectual government policy” (Craig, 2020, p. 1029). In the fight against the spread of the virus, governments have implemented various measures such as mask-wearing, social distancing, quarantining and sanitization. South Africa has moved in and out of the five various alert levels (each with its own degrees of regulation).

South Africa has successfully administered 29 084 975 vaccines as of the 18th of January 2022 (Department of Health, 2022). Despite all these measures within South Africa, 3 564 578 positive cases have been identified and at least 93 551 individuals have died due to COVID-19 (Department of Health, 2022). There remains uncertainty around vaccines, immunity, the severity of symptoms, variants and how long COVID-19 will persist. There are various macro-and-micro-structures and/or factors that potentially influence the illness experience of COVID-19. Structural vulnerabilities are defined as “An individual's or a population groups' condition of being at risk for negative health outcomes through their interface with socioeconomic, political and cultural/normative hierarchies” (Bourgois et al., 2017, p. 2). Various structural vulnerabilities influence COVID-19 infection as illustrated by the Centre for Disease Control (CDC); “Long-standing systemic health and social inequities have put various groups of people at increased risk of getting sick and dying from COVID-19, including many racial and ethnic minority groups and people with disabilities” (2021a). Individuals experiencing various structural vulnerabilities (often divided along the lines of gender, race and class within South Africa) also have a decreased ability to deal with COVID-19 (Team & Manderson, 2020). Culture and religion are also likely to play a major role in the experience of illness with regards to COVID-19, particularly within South Africa as its communities are “diverse and complex, informed by different rules, values and beliefs” (Sambala et al., 2020).

COVID-19 has an ambiguous prognosis, the illness can be mild or life-threatening, its symptoms vary, and its duration is short or relatively long-term in the face of recent evidence for ‘long covid’ (Ladds et al., 2020; Sudre et al., 2021). The severity of COVID-19 has been made more complicated with its interaction with various co-morbidities (such as chronic lung disease, obesity, and immunocompromised individuals just to name a few) (CDC, 2021a). The

CDC has also highlighted the apparent dangers associated with increased age regarding COVID-19 infection - “Older adults are more likely to get severely ill from COVID-19. More than 80% of COVID-19 deaths occur in people over age 65, and more than 95% of COVID-19 deaths occur in people older than 45” (2021b). How individuals experience illness with regards to COVID-19 and the narrative they construct to make sense of it have been influenced by the following factors: structural vulnerabilities, culture, religion, the severity of symptoms, longevity of symptoms, co-morbidities, and age. COVID-19 is a relatively unknown phenomenon, and its illness experience is not adequately understood due to various psychological and social factors impacting how one experiences the illness.

The Illness Experience

The Biomedical model maintained “the belief that illness can be reduced to a pathological lesion, ... within the confines of the body” (Armstrong, 2000, p. 25). This reflects the concept introduced by Foucault of the clinical gaze, where doctors are taught to view and respond to patients and their disease through a biological lens tending to neglect various aspects of language that reflect social and environmental links to their illness (Good, 1994). The clinical gaze focused inwards towards the bodily worlds of the patient, disregarding their speech that relayed their symptoms and ills (Hydén, 1997). However, this began to be challenged during the 1950s with investigations into medical non-compliance and the conceptualisation of the Health Belief Model, offering up psychosocial explanations for health-related behaviours (or health-seeking behaviour). This concept was expected to explain for example, why people choose not to seek medical attention when ill (Armstrong, 2000).

Research surrounding illness behaviour or how individuals responded to their symptoms of illness greatly occupied the field of medical sociology until the 1970s. However, this research had largely failed to provide comprehensible theory and the field was transformed with anthropological and ethnographic studies that began to examine patients cognitions and experiences (Armstrong, 2000). Therefore, “theorizing had to start from the patients understanding of the symptom’s meaning. This meant that health related behaviour could be linked to patients cognitions or lay explanatory models of illness” (Armstrong, 2000, p. 29).

However, the true value of researching an individual’s speech around their illness could only be grasped when a clear distinction between illness and disease emerged (Hydén, 1997). That “disease is the medically defined pathology... Illness is the subjective experience of ill health... [Therefore,] Illness is experienced in time, place and individuality, while disease is abstracted and generalized” (Blaxter, 2010, pp. 20, 22). Therefore, it became clear that patients

themselves could define and make sense of their own illness, meaning that biomedicine could no longer monopolize theories of illness (Armstrong, 2000). These developments provided the framework for the complexities involved in researching illness experiences as explained by Kathy Charmaz:

“I define illness as the person’s experience; disease constitutes a bodily disorder as agreed upon by physicians. Some people do not experience illness when they have a diagnosed disease. Other people experience illness before receiving a diagnosis or being believed to have a disease... It is at once subjective and social; it includes experiencing inchoate emotions and bodily sensations as well as making such experiences meaningful and responding to imagined or actual social responses” - (2000, p. 277)

Initial studies on the illness experience focused on a patient’s subjectivity revolving around how they experienced illness and the meaning they assigned to it, largely examined through “the metaphors, cognitive representations, and images that they developed after learning of their condition” (Pierret, 2003, p. 5). These studies engaged with the patient’s loss of identity as well as experience of shame and stigmatization, how illness impacted upon ones social and occupational relationships and also attempted to explain how the social structure impacted upon one’s experience of illness (Pierret, 2003).

A standout theorist during this time of research was Michael Bury who examined chronic illness and related it to that of a major disruptive life event (Pierret, 2003; Williams, 2000). Bury, in his 1982 paper ‘Chronic Illness as Biographical Disruption’ critiqued medical sociology for its oversimplified identification of “medical thought with disease and lay thought with illness” (p. 179). Instead, Bury suggested that medicine be viewed as a cultural system that is a resource in times of distress and pain and a constraint to individuals trying to make sense of the meaning they assign to their experience of illness (1982; Pierret, 2003). Bury, also illustrated that the disruption to one’s life is impacted based on how the illness disrupts their social relationships and their ability to mobilize material resources to adapt to the disruption caused by the illness, of which the latter involves various social structures (1982). Therefore, how one experiences illness is influenced by an array of socio-environmental factors.

Bury’s concept of illness as a disruption offers scholarly insight into the experience of illness, various scholars debate illness as a disruption versus a continuity (Charmaz, 2000;

Williams, 2000). Illness as a continuity argues that illness cannot be limited to a single disruptive event but rather effects over a very long term. Examples of this is a chronic illness, difficulties gaining a diagnosis and treatment, living with symptoms that aren't recognized by doctors, etc (Charmaz, 2000). Williams takes this further implying that illness is a condition of modernity, saying that individuals are caught in a constant system of 'body surveillance', that individuals encounter a never-ending-cycle of 'body maintenance', 'self-improvement' and 'risk-avoidance' and therefore, the body constantly needs to adapt to not fall ill (Williams, 2000). Illness can cause life-long identity change or fear of getting the illness again, causing people to formulate new narratives about their lives (Frank, 1997a). Therefore, the concept of the illness cannot just be limited to the immediate disruption the disease causes.

Arthur Kleinman has also broadened the conceptualization of illness experience, specificity looking at illness as suffering (Hydén, 1997), as seen in the following quote:

“The problem of illness as suffering raises two fundamental questions for the sick person and the social group: Why me? (the question of bafflement), and What can be done? (the question of order and control) ... Suffering is not easily put aside by biomedical science; [but] it remains central to the experience of illness, a core tension in clinical care” - (Kleinman, 1989, p. 29,30)

Therefore, the illness experience doesn't impact an individual solely while they are subjected to the symptoms of their illness but on a wider temporal framework. The questions of 'Why me?' and, 'What can be done?' resonate closely with Arthur Frank's paper 'The Rhetoric of Self-change' referring to illness as an epiphany where the individual reflects on 'Who I Always Have Been' and 'Who I Might Become' (1993). Therefore, experiencing illness requires individuals to assign meaning not just to their symptoms but to their larger social world as well as making sense of their past histories and imagined futures. This is the process of constructing an illness narrative and will be elaborated upon in the next section. However, it is important to offer an example of the illness experience of COVID-19, which is provided by Callard using the diagnostic criteria of mild COVID-19 as an example:

“While for many mild Covid-19 has been experienced as mild, others have undergone significant suffering. For many, physical symptoms have been awful and have lasted much longer than two weeks But it's also

important to make clear that no matter how mild (or not) an individual's experience of Covid-19 illness is judged to be, many have found it affectively and psychologically intense to manifest symptoms of a new disease without knowing what might unfold in the course of illness" - (2020, p. na)

This would suggest that the generalization of illness still presents as an issue with regards to COVID-19, this is perhaps because "the assumption of the 'generalizability' of illness is a part of our modern nomothetic mythology about disease, which assumes a uniformity of experience within a diagnostic category" (Hawkins, 1999, p. 5). The passage indicates that the experience of COVID-19 may be experienced as merely a disruption or a continuity with the various effects (physical or psychological) having a longer temporal effect on the individual. The uncertainty of COVID-19 calls individuals to use illness narratives as a means of making sense of the strange world in which they find themselves, where their experience of illness doesn't reflect the same experience of others... the individual is left to make sense of their illness themselves.

Illness Narratives

"Everyone who is born holds dual citizenship in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place" - (Sontag, 1978, p. 3)

Arthur Frank, in his book 'The Wounded Storyteller' refers to Sontag's notion of dual citizenship when introducing his concept of The Remission Society – "The remission society is left to be either a demilitarized zone in between them [health/illness citizenships], or else it is a secret society within the realm of the healthy" (Frank, 1997a, p. 9). His concept of The Remission Society refers to the fact that even when people have been 'cured' of their illness, some never return to a state of good health. Some examples he postulates are those who have gone through cancer, those with heart conditions, disabilities, the chronically ill, and those recovering from abuse and addiction. Others live with 'invisible' illnesses that can be exposed at any time, such as someone having to announce that they have a pacemaker at airport security

(Frank, 1997a). This emphasises how one might experience adverse circumstances due to illness, long after the illness has passed. The narrative is used to make sense of the new realities experienced:

“The concept of narrative underpins examination of the ways in which people give meaning, sense and structure to the trajectory of their illness... Even relatively minor symptoms occasion people suffering illness to question aspects of their lives, seeking to find satisfactory explanation for their sickness” - (Lupton, 2012, p. 86).

For Frank (1997a), the narrative is a means of reclaiming one’s voice that has been lost to biomedicine. The illness narrative allows the individual to make sense of the illness in various ways. The narrative does this in one way - “By arranging the illness symptoms and events in temporal order and relating them to other events in our lives, a unified context is constructed, and coherence is established” (Hydén, 1997, p. 56). This means the individual can relate the illness to past histories and imagined futures, assessing the temporality of the illness, for example, how long will the pain last or how painful is this illness in relation to pain that I have felt before? Narratives also allow for a reconstruction of one’s identity and critical reflection of one’s history. As Hyden quotes - “The illness is the vantage point from which all other events are viewed and to which all other events are related” (1997, p. 57). The individual assesses how one’s life might change and if they will still be able to be the same person they were before the illness. There is also an emphasis on the moral aspect of confronting illness (Lupton, 2012) which is a pivotal part of understanding the illness - “The event of an illness forces us to ask ourselves if there is a connection between the illness, on the one hand, and our moral values and how we live our lives, on the other” (Hydén, 1997, p. 58). This allows the narrative to provide an explanation of the illness, not just for the ill individual but also for those with whom they share the story with (Hydén, 1997). Illness narratives can also turn from personal to collective narratives (Pierret, 2003), for example, HIV/AIDS narratives were constructed to find listeners (Hydén, 1997), in that these narratives relayed collective struggle.

Although illness narratives can be used to relay collective struggles and gain social support, it must also be acknowledged that illness narratives themselves “deal with events and experiences as constructions of inner and outer worlds” (Lucius-Hoene, 2018, p. 13). Meaning that no one can construct their illness narrative outside of their own social context. One cannot begin to create their own understanding of illness without being influenced by the social

circumstances in which they find themselves. Expanded upon by Carol Thomas as she reflects on her work around illness narratives and cancer as an example, “I think that the stories that patients and carers tell about their experiences of living with cancer are socially constructed accounts that express the meanings that real events and social circumstances have for them” (2010, p. 656). An illness narrative, therefore, is not formulated in isolation, it is a complex interplay between events and social circumstances and how the individual uses these to make sense of their illness. The individual’s social context is an important resource with regards to how an individual comes to understand their illness. The social context also plays a major role in how an individual both interprets and responds to a disease. This is of particular importance during COVID-19, given its propensity for rapidly changing social contexts, as illustrated:

“COVID-19 has revealed a blurred conceptual divide between illness and wellness; between medical and social risks; between safety and harm. Narrative contexts such as the workplace, the home, schools, the community, and health-care settings have shifted in meaning in this pandemic. These changes continue to shape the way we think about and respond to COVID-19” - (Gubrium & Gubrium, 2021, p. 2245)

Risk Narratives

COVID-19 has influenced an individual’s life narrative by proliferating them with uncertainty and risk. Ann Jurecic (2012) in her book ‘Illness as Narrative’ adds insight into these effects, particularly in chapter two, titled ‘Life Narratives in the Risk Society’. The concept of the risk society was originally coined by Ulrich Beck in the ‘Risk Society: Towards a New Modernity’ (Jurecic, 2012; Leiss et al., 1995). The risk society reflects the increased proliferation of health statistics that have accompanied modern times. The result is that individuals within society are increasingly aware or anxious of risks, these create risk narratives that are used “to make sense of or contain the sense of being at risk of disease, accident, or death” (Jurecic, 2012, p. 20). A consequence of living in a world that is proliferated with risk statistics is that “individuals define themselves through life narratives that are shaped by uncertainties and choices rather than through tradition” (Jurecic, 2012, p. 20). With increased risks and uncertainties due to COVID-19 individuals would find it more difficult to find or experience ‘cocoon of invulnerability’, a phrase originating from Deborah Lupton (1999) that refers to experiences or places “that allow temporary respite from the risks and uncertainties of everyday life, moments of self-

transcendence that feel beyond the particular and individual, and thus beyond vulnerability” (Jurecic, 2012, p. 38).

Individuals are more aware of their vulnerabilities due to the barrage of health statistics on COVID-19. This means before one even catches the disease, they most likely have constructed a narrative of what they think would happen. Also, after diagnosis, the individual has an expected prognosis. For example, ‘I am young and healthy, I don’t have any comorbidities, I am most likely to get flu-like symptoms and recover within 10 days’, conversely, ‘I am over 60, and have diabetes, I think I will go to the hospital, and it will be longer than 14 days’. Jurecic (2012) illustrates that these assumptions due to statistics do not necessarily reflect the actual illness experience, therefore the statistics first have a great propensity to create fear and anxiety of catching the virus and secondly can create confusion and bewilderment when the illness experience doesn’t correspond to the expected statistics. Illustrated by Jurecic – “There is a fundamental incompatibility between personal memoir and statistics: while general populations can be described with probabilities, the life [or illness experience] of an individual cannot” (2012, p. 21). Risk narratives around COVID-19 will play a role in how an individual experiences the illness as well as how they make sense and establish an understanding in the face of uncertainty.

Types of Illness Narratives and Long COVID-19

Frank (1997a) postulated three types of narratives told during illness, namely, restitution, chaos and quest. These were proposed as an analytic framework when dealing with illness narrative research (Allison, 2021). Restitution refers to those who give their body over to medicine and recover from their illness, where the individual gets their former ‘predictability’ of life back, largely as a result of biomedical intervention (Frank, 1997a). Chaos is positioned as opposite to restitution, in that the story is told in the absence of order and coherence, the experience is only explained through the individual’s attempts to relay dialogue about their illness (Frank, 1997a; Rushforth et al., 2021). Quest narratives reflect those who view their illness as an experience in which something can be gained or an experience that provides a higher purpose (Frank, 1997b; Rushforth et al., 2021). These concepts explain in the words of Frank, “Restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head-on; they accept illness and seek to use it” (1997a, p. 115). However, the use of these has gained contemporary criticism with regards to the analytical function of

these categories (Atkinson, 2009; Rushforth et al., 2021). Nevertheless, they provide some insight and themes regarding the content of illness narratives.

Narratives around long-COVID are also somewhat contested, particularly because the symptoms of long-COVID do not confer to the established diagnosis and prognosis of COVID-19 as elaborated upon by Rushfield et al: “In early 2020, Covid-19 was depicted in clinical publications as a short-lived respiratory illness (often described as a ‘pneumonia’) with a defining triad of symptoms: fever, breathlessness and cough... [although] Long Covid’s protean manifestations contrasted starkly with official emphasis on a clearly demarcated defining triad. Symptoms were inconsistent and vague, affecting any or many-body systems and came and went without rhyme or reason” (2021, p. 4). This creates an issue as those experiencing long-COVID often refer to it as ‘weird’, ‘strange’, or ‘odd’, and encounter issues due to no identifiable pathology that could lead to a diagnosis. This makes it hard for the afflicted to relay their experience to others (Rushforth et al., 2021). Work on chronic pain has been well documented within the literature as encountering this similar problem, as illustrated by Danielle Kohfeldt and Gregory Mather speaking on their issues of experiencing chronic pain - “[d]ue to the lack of identifiable pathology for my pain, medical practitioners expect me to recover” (Bolt, 2021, p. 144). The issue with long-COVID is that the individual is left to recover by oneself, to explain, ‘weird’, ‘strange’, and ‘odds’ symptoms to those who may not acknowledge them, and in the mists of this hope to recover. These individuals are left in a space of vulnerability, suffering, and pain, all of which serve as barriers in one’s attempt to provide meaning, coherence, and understanding to illness.

Therapeutics and Narrative

In the absence of coherence around illness, narratives and storytelling can serve as therapeutic tools. This is reinforced by academics such as Frank and Kleinman who view illness narratives and storytelling of illness as a great therapeutic resource for those struggling with illness (Thomas, 2010). It is important to illustrate that illness narratives and the stories they tell not only allow for the construction of understanding for those afflicted by the disease, but these narratives also allow for distant others to hear stories of illness and understand it themselves. For Frank, the principal means of illness narratives is to focus on the ethical and moral implications of listening to stories of illness, namely, to individuals gain coherence and understanding of illness. Illustrated by Frank - “My work, deriving from the standpoint where choice and chance have left me, is to listen to the ill: to attempt to give their stories greater currency and to help ill people and those who are not yet ill to hear the wisdom in illness

narratives” (2000, p. 363). Although illness narratives can offer these insights, academics have criticised the role of illness narratives within sociology, indicating that illness narratives put the researcher in a problematic situation where they are stuck between therapeutics and adequate analysis of illness narratives. For example, Paul Atkinson questions the use of ethnography within sociology due to the moral implications that may distort the reliability of data, calling for formal discourse analysis and acknowledgement of social facts that can be systematically analysed (2009; Thomas, 2010). However, literature around illness narrative methodology remains a ‘contested terrain’ (Thomas, 2010) of some consensus is that methods need to account for both the therapeutic nature and inquiry into social analysis when researching illness narratives. A framework for attempting to incorporate both these aspects is introduced in the methodology, however, before discussing this aspect of the research report it is important to address literature around metaphors, stigma and idioms of distress which are concepts that aid in the analysis of illness narratives.

Metaphors, Stigma & Idioms of Distress

Metaphors are defined as a “figure of speech that implies comparison between two unlike entities... [that makes a] qualitative leap from a reasonable, perhaps prosaic, comparison to an identification or fusion of two objects, the intention being to create one new entity that partakes of the characteristics of both” (Britannica, 2017, p. na). Metaphors are prevalent tools for individuals in expressing concepts and experiences that are hard to comprehend and even harder to express in language. Vallis & Inayatullah provide an explanation for this in the following quote, “metaphor goes beyond language ... It is pervasive in our thoughts and actions because the ways in which we think, perceive and act are metaphorical in nature. Our conceptual system is metaphorical, thus we experience the world in metaphors” (1997a, p. 115). Metaphors with regards to illness are used to derive meaning from illness, to equate the ‘real world’ to ‘the body’ (Sontag, 2003). This is because “acting like a sponge, illness soaks up personal and social significance from the world of the sick person - (Kleinman quoted in Annandale, 1998, p. 255). Annandale highlights two embedded meanings within this quote, that we cannot make sense of our own illness without understanding the social world around us and that illness is highly metaphorical (1998).

The use of metaphors during outbreaks of infectious disease is no new phenomenon. The most widely used metaphor during outbreaks of disease are those classified as ‘war-like-metaphors’. These have been widely documented among authors studying discourse analysis of newspapers during various outbreaks of infectious disease, namely, HIV/AIDS (Kothari,

2016), Ebola (Moodley & Lesage, 2020), SARS (Wallis & Nerlich, 2005), and COVID-19 is not different (Craig, 2020; Joubert & Wasserman, 2020). Hence, epidemics and their disease are habitually described as ‘waves’, ‘tides’, ‘invaders’, ‘killers’, and ‘predators’. Therefore, metaphors are not just used as a tool for the individual to describe and make sense of their own illness, but metaphors inherently influence how individuals understand the epidemic and viruses themselves. The use of metaphors is a good tool in researching individual illness experience as - “Illness metaphors make inchoate experience comprehensible ... Metaphors offer more than reductionist or comparative views; they illuminate, enliven, and evaluate experience” (Charmaz, 2000, p. 278).

“Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious” - (Sontag, 1978, p. 5)

Of big issue with regards to viewing illness metaphorically is the propensity of metaphorical think to create stigmatisation and fear. Sontag’s project in illness as Metaphor was to “counter popular and literary accounts of illness that perpetuate stigmatizing myths that diseases... [are] caused by moral failure and signify social disorder” (Jurecic, 2012, p. 62). However, this is problematic as our conceptual system thinks metaphorically as previously stated and even Sontag was not free from the use of metaphor as her metaphor of the kingdoms of the well and the sick is still quoted widely within academia (Jurecic, 2012). Metaphors and stigmatization for the meantime are fixed in the experience of illness.

Stigma is “a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group.” (Scambler, 2009, p. 441). Interactionist and labelling theories introduced the concept of stigma in the 1970s. One of the most important academics in developing this concept during this time was Goffman (Armstrong, 2000; Scambler, 2004). The concept of identity is central in Goffman’s work. For Goffman, stigma arises when there is a discrediting inconsistency between an individual’s virtual social identity (features, qualities, and classifications found within one’s daily social interactions) and their social identity (the actual features and attributes an individual owns). This inconsistency between actual and virtual social identities entails that the individual will have a permanently discrediting feature that results in their stigmatisation. This feature becomes a defining characteristic of their identity (Weinstein, 1965). When an individual is

stigmatised or given certain labels based on a certain characteristic they are “thus reduced in our minds from a whole and usual person to a tainted, discounted one” (Goffman, 1990, p. 12).

Stigma can be experienced directly or indirect, or in other words, stigma can be enacted or felt. Enacted stigma signifies “episodes of discrimination against people with [an illness]... solely on the ground of their social and cultural unacceptability” (Scambler, 2004, p. 33). While felt stigma is related to both internalized stigma (shame over the acceptance of stigmatised attributes), and anticipated stigma (fear over encountering future prejudice or stigmatisation) (Peltzer & Pengpid, 2019; Scambler, 2004). Scambler indicates that “the fear of enacted stigma promotes a policy of non-disclosure that remains viable as long as people are discreditable rather than discredited...” (2004, p. 33). A policy of non-disclosure adversely affects the uptake of certain treatments and health care seeking as individuals are scared to disclose their status over the fear of being stigmatised, as illustrated by Abboah et al (2020) and their research on HIV/AIDS within South Africa. Therefore, stigma negatively impacts effective healthcare intervention and can greatly affect the level of social interaction available during outbreaks of infectious disease and consequently impacts on how individuals experience, react to and comprehend an illness within society.

Metaphors and stigma often relay characteristics of distress during times of illness. However, distress can also be relayed in idioms of distress which “are socially and culturally resonant means of experiencing and expressing distress in local worlds” (Nichter, 2010, p. 405). Idioms of distress are typically manifestations of psychosocial distress that have either personal or cultural meanings and are often employed when one does not have the means to adequately ventilate their distress and frustration (Desai & Chaturvedi, 2017). Idioms of distress can be thought of as cultural or personal modes of expression and “are considered as adaptive responses in circumstances where other modes of expression fail to communicate distress adequately or provide appropriate coping strategies” (Desai & Chaturvedi, 2017, p. 95). Idioms of distress have been employed during specific times of social distress to gain an understanding of the psychosocial trauma experienced following these phenomena, particularly where western conceptualisation of mental illness may not be particularly accurate. For example, research examining idioms of distress following the Cambodian War (Kidron & Kirmayer, 2019) and the Nepali War (Kohrt & Hruschka, 2010). One strength of idioms of distress is their questioning of western explanatory models of mental illness which tends to place responsibility on the individual. Instead, idioms of distress emphasise the collective nature of distress and psychological trauma resulting from periods of precarity (Summerfield, 1999). In essence,

psychological health can particularly be influenced by how collective cultures respond to social issues. This could be of particular importance for understanding the impact of COVID-19 and how individuals and collectives deal with its trauma.

It is evident that the social worlds in which individuals find themselves during the COVID-19 pandemic will greatly impact an individual's own understanding and response to COVID-19 illness. Therefore, metaphors, stigma, and idioms of distress can help explain the impact of the social world on the experience of one's illness. Metaphors, stigma, and idioms of distress can all be present in illness narratives (Groleau et al., 2006) and therefore were identified and used to explain the illness experience of COVID-19 and its relation to the social context.

Impact of the Literature Review

The literature review has indicated that the COVID-19 pandemic has fundamentally changed societies in a variety of ways, namely, through shifts in conceptualisations of health and illness, safety and risk, healthcare settings, and meanings assigned to communities, homes, schools, workplaces, etc (Gubrium & Gubrium, 2021). The experience of COVID-19 itself can be drastically different as even those classed with mild COVID-19 infection can experience an enormous difference in severity and temporality of the illness (Callard, 2020). Both the social aspects and physical impact of having the disease can impact health, illness, and wellbeing over a period that is not yet known. Hence, the use of illness narrative literature of authors who typically deal with chronic afflictions. The broader impact of COVID-19 is not yet adequately understood and can only be examined through a lens that accounts for both varied social contexts and illness prognosis. The subjectivity of individuals experiencing COVID-19 are important and unresearched, research needs to relay the complexities of the COVID-19 illness experience and its impact on life narratives. Therefore, the effects on the individual the interrelation of their social contexts are not adequately understood. This importance is illustrated in the following quote, - "As we come into contact with embodied, ordinary and extraordinary experiences of illness, medical discourses and clinical institutions, our stories contort, breakaway and merge while remaining firmly embedded in larger historical, institutional and culturally specific structures" (Kokanović & Flore, 2017, p. 337).

Therefore, the impact of COVID-19 greatly differs depending on a variety of social, historical, and individual factors. While work has been done on assessing the commonalities of COVID-19 illness narratives, these have typically been done in a digital space given the impact of the pandemic (Allison, 2021). Research needs to be done on first-hand accounts of

the COVID-19 illness experience that attempt to lattice the rapidly changing social context and precarious illness experience of COVID-19 to provide a more nuanced comprehension of how COVID-19 affects individuals. This more nuanced comprehension allows for enquiry into the risk perceptions and how individuals must make risks personal to understand them, the therapeutics of narrating one own illness experience, and the metaphysical nature of the illness. In essence, a view outside of the clinical lens of COVID-19 needs to be established if we are to begin to understand the truthful impact of the pandemic and lived experience of COVID-19.

Methodology

Research Design

This research report follows a qualitative research design that sought to interview individuals that had also experienced COVID-19 infection. Qualitative research focuses on “human intentions, motivations, emotions, and actions, rather than generating demographic information and general descriptions of interaction” (Adams et al., 2015, p. 21). The interview questions and analysis were led and adapted from The McGill Illness Narrative Interview (MINI) (Groleau et al., 2006) which will be discussed in greater detail in the subsequent section. The research design is focused on the in-depth interviews to gather illness narratives combined with the use of autoethnography as a means of gathering in-depth information on the experience of COVID-19 to gain an understanding of COVID-19’s effects within the socio-cultural system of the middle to the upper-class population of South Africa, particularly among a majority white population. Although a sample of a majority white population was not the original intention, the use of a snowballing method resulted in this homogenous group. The research report was then revisited to best provide insights into the population.

Narrative Based Research and Interview Questions

The McGill Illness Narrative Interview (MINI) is used to interpret ‘modes’ of reasoning and the meaning that individuals assign to their illness experience. It is suitable for a wide range of fields, including medical sociology (Groleau et al., 2006). The MINI framework emphasises the use of qualitative interviews as - “qualitative interview research shares a constructivist perspective that views the speaker or interviewee as actively involved in meaning making” (Groleau et al., 2006, p. 672). This supports the previously mentioned literature on the importance of meaning-making during the illness experience. A constructivist perspective also

coincides with the importance placed on the subjectivity of the illness experience as – “A constructionist approach takes the subjective experience of illness seriously, examining the personal and social meanings of illness” (Conrad & Barker, 2010, p. 572). The MINI acknowledges that both the personal and social context cannot be viewed outside one another (Groleau et al., 2006).

Given the complex nature of examining illness narratives, the MINI uses three types of reasoning to represent illness, namely, Explanatory Models, Prototypes and Chain-complexes (Groleau et al., 2006). Explanatory models “are based on causal thinking which may involve conventional models, causal attributions or more elaborate models involving specific processes or mechanisms” (Groleau et al., 2006, p. 676). This examines the reasons individuals give for their illness, for example, ‘I got sick because I eat badly’. Prototypes “involve reasoning based upon salient episodes or events in one’s own or others’ experiences, which allow individuals to elaborate the meaning of their illness through analogy” (Groleau et al., 2006, p. 676). This examines events that have influenced the individual and their perception of an illness. Chain-complexes occur when “past experiences are linked metonymically to present symptoms through a sequence of events surrounding the symptoms without any explicit causal connection or salient prototype” (Groleau et al., 2006, p. 676). Chain-complexes look at how individuals link certain events together to make sense of why something occurred. The MINI is examined ‘retrospectively’ even though ongoing symptoms may persist (Groleau et al., 2006). This coincides with narrative psychology as Bradbury states - “The significance of a particular event can only be identified in terms of its later effects” (2019, p. 24). The MINI provides a guide to systematically assess the illness narratives of individuals to gain coherence over their story, considering both the personal and social factors and their influence. Therefore, the MINI offers a good guide to access the personal and social impacts on the COVID-19 illness experience.

The interview questions were adapted from the McGill Illness Narrative Interview (MINI) found in the appendix of (Groleau et al., 2006). The research questions consisted of four sections namely, (1) Initial Illness Narrative, (2) Explanatory Models, (3) Help-Seeking and Service Utilization, and (4) Impact of Illness (Groleau et al., 2006). The adapted questions used in this research report can be found in appendix A.

(1) Initial Illness Narrative

These questions aimed to get the participant to tell their own story in their own way, as well as probe possible prototypes and disease labels. It is important to note that there was no limit on these responses and the interviewees were encouraged to share as much

as they could (Groleau et al., 2006). Essentially the aim was to get a “narrative of events related to the illness in an organized way, considering time and space” (Santiago et al., 2014, p. na). It is important to note that this section was not fixed in structure but rather followed open-ended questions that served as prompts from the interviewee.

(2) Explanatory Models

This section aimed to “elicit narratives that allow[ed] the acknowledgement of the explanatory models that the person interviewed built to understand the cause(s) of their illness” (Santiago et al., 2014, p. na). This section looked at how one reasoned with their illness to explain it, this section highlighted metaphors, stigma, and idioms of distress.

(3) Help-Seeking and Service Utilization

This section aimed to get a “narrative of their experience with health services and hospitalization, and their response to received treatment” (Groleau et al., 2006, p. 682). Given the uncertainty around the treatment of COVID-19, it offered valuable insight into the experiences of COVID-19.

(4) Impact of Illness

This section examined how the individual believed their life had changed due to their illness, assessing if individuals believed they have experienced changes to their identity and/or way of daily life (Groleau et al., 2006). This section was also adapted to assess the community, collective, and social change because of COVID-19.

Autoethnography

Autoethnography was chosen as “it offers nuanced, complex, and specific knowledge about particular lives, experiences, and relationships rather than general information about large groups of people” (Adams et al., 2015, p. 21). The choice of autoethnography over traditional ethnographical methodology stems from the fact that I had contracted the COVID-19 virus at the end of 2020, and this was a large driving factor for why I chose to undergo this research. Positioning myself within the research report has allowed space from my own critical reflections of COVID-19 among a group of which I am already a part. In this way, a more nuanced and in-depth analysis of COVID-19, its experience and the illness narratives told can be discussed and analysed.

The literature review has clearly indicated that there are more vulnerable populations that experience greater adversity in the face of COVID-19 due to various structural vulnerabilities and the group of which I am a part is not the most vulnerable to the impact of COVID-19 (i.e., individuals within this group have been able to better isolate, seek medical attention, etc). However, the illness experience of the virus varies greatly and its effects on the individual and social context are not adequately understood. The selection of this group was also influenced by the COVID-19 pandemic, as it was difficult to find participants willing to speak about their experience of COVID-19 given its precarious and uncertain nature (i.e., individuals did not know how the virus would impact them from day to day). Therefore, to mitigate the risk of causing harm, participants were interviewed from close networks to myself using a snowballing method. In this way, I was able to gather accurate insight and background with regards to the circumstances they were dealing with.

This may raise questions to the validity of the research report, an issue common with regards to using autoethnography as a research method (Ellis et al., 2010). However, it is important to note that autoethnography is not necessarily concerned with issues that need to be resolved but rather it illustrates that different viewpoints and experiences to be lived (Ellis et al., 2010), of which COVID-19 and its illness experience needs future exploration. Therefore, rather than focusing on generating concrete results, this research report pays particular attention to three main questions that are present when conducting autoethnography, namely, “who reads our work, how are they affected by it, and how does it keep a conversation going?” (Ellis et al., 2010, p. na).

Method for Data Collection and Sample

The data collection method was a semi-structured, qualitative, open-ended interview that lasted approximately 60 to 90 minutes per participant with the possibility of follow up interviews depending on the information gathered. The participants were selected through a snowballing method from 8 original participants from whom the researcher had access to (these were individuals in close circles to the researcher, i.e., family members, friends, etc). Most of the participants experienced what would be classed as mild-COVID-19 infection (only one participant was hospitalised due to COVID-19, however, at the time of the interview they had made significant recovery). All participants were drawn from a middle to upper-class community, being 18 years or older and having had a previous COVID-19 infection. Although this group was not the most vulnerable to the impact of COVID-19 (i.e., individuals within this group can better isolate, seek medical attention, etc) it included a variety of conditions to gain

an understanding of COVID-19, namely, diverse experiences, ages, symptom severity, duration of illness, and explanatory models. The snowballing method gained 11 participants in total for the study. All interviews were conducted in English. The interviews were done both online (through a virtual platform i.e., zoom, teams) and in-person. Only those who were in close family contact were allowed to be interviewed in person to mitigate the spread of the COVID-19 virus. In either case, the interviews gained the participant's permission before commencing, they were audio-recorded with permission, transcribed, and analysed.

An overview of those who participated in the research report is provided in the following table (Figure 1). The table lists the interviewer code (randomly assigned three-digit number) and provides a more descriptive background for those interviewed and their experience of COVID-19. This is provided to contextualise the findings while still maintaining the anonymity of the participants.

Figure 1: Overview of Participants within Sample

Overview of Sample					
Code	Age	Sex	Temporality	Formal Help-Seeking	Description
001	80s	Female	Long	Hospitalization	Hospitalized during the second wave of infections. Hospitalization occurred for two weeks, with a further two weeks at a 'step-down' facility for monitoring. While in hospital she received two negative COVID-19 tests but received the results of her PCR test that she took before going into the hospital stating that she was positive for COVID-19 infection. She reported feeling very disorganised and not knowing what was going on during her stay in the hospital, due to a lack of information provided by doctors. She expressed frustration at the fact that she didn't know if she had COVID-19 or what she was being treated for during the first two days of being in hospital. Experienced brain fog and fatigue as long-term symptoms of COVID-19, however, it was reported that these

					symptoms had gotten significantly better a few months after infection.
021	50s	Female	Short	Online Contact	Relatively minor symptoms consisting of a dull headache, 'lump in the throat', and slight difficulty with breathing. This participant was asthmatic. She was able to speak to a doctor over the telephone who advised her what medication to take. She had no long-term symptoms after the two weeks.
074	20s	Male	Short	No Contact	Relatively asymptomatic but recalls the possibility of a slight cough.
043	20s	Female	Long	In/Online Contact	Participant caught COVID-19 twice, in the first and third waves. The first experience was relatively short with little to no symptoms. The second experience was a lot worse. Symptoms described were nausea, vomiting, fatigue, loss of taste and smell. Symptoms of long-covid persisted months after infection up and beyond the interview, with long term symptoms being extreme fatigue, difficulty focusing, heart issues, and not being able to exercise. Help-seeking behaviour entailed both traditional western medicine (general doctor as well as cardiologist) and a homeopath.
065	20s	Male	Short	Via-Via	Participant had to look after family members after the third wave of infections who had contracted the virus. He contracted the virus from looking after one of the family members who was severely ill. His own symptoms consisted of a fever, rash, body aches, loss of smell extreme fatigue. The only symptom that was reported to last longer than a two-week period was a loss of smell.
091	50s	Female	Long	Via-via/ Online	The participant used a doctor in her neighborhood as a means of help-seeking. They managed her prescription and follow up with her daily. Her symptoms consisted of

					nausea, vomiting, and an intense cough. Symptoms that persisted long term were difficulty with memory or as described as having a 'porridge brain' as well as difficulty with managing her asthma post-COVID-19.
079	20s	Female	Short	Online Contact	Participant caught COVID-19 during the second wave of infections within the country. She had a variety of symptoms that tended to change daily over a ten-day period. Symptoms could come and go and consisted of nausea, difficulty breathing, diarrhea, fatigue, and a dry cough. No long-term symptoms were reported.
036	30s	Male	Short	In/Online Contact	Participant caught COVID-19 twice, once after the second wave, and the second time after the third wave in the country. Symptoms were described as the same as flu-like symptoms, apart from the first night of the first infection where he had intense night sweats and a fever. He reported no long-term symptoms.
018	20s	Female	Short	Via-Via	Participant caught COVID-19 during the second wave of infections in the country. She had relatively no symptoms apart from one of which she described as a 'weird burning in her nose' that last for a couple days. She recounted the hardest factor of COVID-19 as being the psychological effects of living through a pandemic and having to isolate when sick. She was monitored through a family member who had contact with a friend who was a doctor but took no further action as symptoms did not develop further. No long-term symptoms were reported.
096	20s	Male	Short	No Contact	Participant reported symptoms of bad headaches and fatigue for a period of five to six days. He also reported losing his sense of taste

					and smell for a shorter period. Those within the household in which he was living have still not regained their sense of taste. The only long-term consequence reported from having COVID-19 was an interference with his co-morbidity of psoriasis.
057	20s	Female	Long	In Person Contact	Participant caught COVID-19 round the third wave of infections within the country. She described her symptoms as 'having a little bit of everything', including difficulty breathing, extreme fatigue, fever, and a rash which occurring on her face and neck. These symptoms got worse over the course of a few days, so she went to the doctors for confirmation that she had COVID-19, however she tested negative to a PCR test. The doctor however reaffirmed that she did in fact have COVID-19. She was still dealing with symptoms of long COVID months after her infection as she claims that she still struggles to climb stairs due to the fatigue that has remained post COVID-19 infection.

Analysis of the Data

The data from transcripts were analysed to produce “narratives that [could] be analysed according to their form or structure (e.g., genre, plot, characters, temporal structure, modes of reasoning) or their content (e.g., themes, images, metaphors)” (Groleau et al., 2006, p. 683). Transcripts were uploaded to the qualitative computer software, Atlas.ti 22 Mac, version 22.0.0 (3222) (*Atlas.Ti*, n.d.), and analysed according to codes created from the literature and guidance of the MINI (Groleau et al., 2006). This process created a framework in which the interview could be arranged according to three sets of codes, the first being temporality, the second, modes of reasoning, and the third, themes. Codes under temporality were divided into subcodes, namely, past histories, illness experience, and imagined futures. Past histories examined past tense reflections, illness experience, diagnosis, symptoms, treatment, and service utilisation (or help-seeking behaviour). The code, ‘imagined futures’ examined texts where the individual offered future contemplation because of COVID-19. The second set of

codes examined modes of reasoning, namely, chain-complexes, prototypes, and explanatory modules (these were future sub-divided into metaphors, stigma, and idioms of distress), to gain a better understanding of the meaning and understanding individuals assigned to their experience of COVID-19. Thirdly, codes were developed according to themes, namely, disruption, continuity, long-covid, fear, and uncertainty. These resulted as common themes were found amongst those interviewed. Thereafter, the texts found within each code were future refined assessing where codes overlapped as well as their position within the context of the longer interview. This allowed for a more coherent understanding of the illness narratives provided by the interviewees which were contrasted with my experiences during and out of the interviews. Autoethnography allowed me to contextualise the data and offer up self-reflexivity in discussion to provide better insight into how one comes to understand an illness through social connections and experiences.

Limitations

I acknowledge that there are potential limitations given the relatively small sample size, particularly in relation to what the sample can represent on a large scale, i.e., this relatively small sample cannot accurately represent all the various experiences and encounters of COVID-19. Therefore, the generalizability of the study could be questioned, however, one important aspect of conducting this research was to illustrate that the experience of COVID-19 cannot be generalised, and the great complexity of research COVID-19 is the sheer variability of its experience. This means that even though the sample is homogenous with regards to race and language (most of the sample are white and English speaking) it cannot and should not be used as a generalization of experience for this group. As the researcher, I realise that the sample does not reflect many important voices and experiences of other groups and hope that this research will encourage further investigation into the effects of COVID-19 among various groups. This is also particularly important as this sample group was not the most vulnerable group affected by the COVID-19 pandemic. Online interviews also presented a limitation particularly with the use of autoethnography as a method as I felt that this served at times as a barrier to gaining better insights during the interview process. I also feel that a potential limitation of this research study was the complex environment in which the research took place, namely, the sensitive nature of the topic, a precarious COVID-19 environment, and a need to mitigate distress from the participants. I, as the researcher felt at the time that I would avoid certain questions if I had a sense that the interviewee was uncomfortable, although I do feel

this was necessary to protect those interviewed, I do feel that some of the deep traumas and emotions of the COVID-19 pandemic would not be adequately reflected in this research.

Ethical Considerations

Given the sensitive nature of researching illness and the uncertainties surrounding the COVID-19 pandemic, various ethical considerations were introduced into this research report to best ensure the protection of those involved. All participants were of adult age (18 and over) and were targeted to be within the middle to the upper class within South Africa. The selection of these classes followed the ideology that they should be most likely to be able to shield themselves from the COVID-19 pandemic, i.e., this group would have more resources to isolate, they would have more chance of obtaining medical care, etc. This was done to try and select individuals that had the highest likelihood of not experiencing compounding effects of the pandemic (i.e., a rapidly changing environment causing stress, and this compounding with existing/worsening structural vulnerabilities) to best try and avoid participants becoming distressed during interviews. Although this precaution was taken, I knew individuals could become distressed during interviews as I had witnessed various close others having to deal with stress and trauma because of the COVID-19 pandemic. For this reason, a research protocol was established in the event a participant became distressed during the interview process. It was agreed that participants would receive formal copies of the interview questions before they commenced with the interview, this way participants were able to see what type of questions they would be asked beforehand and therefore could decline to partake in the interview if they thought it would make them uncomfortable. Participants were also issued with telephone numbers to free psychological services and a psychologist in the area briefed on the research being conducted. If the individual did agree to be interviewed after seeing the questions and still became distressed during the interview a research protocol was established, in which the formal interview was stopped. I would then try my best to calm the situation and provide comfort to the participant. During this time, I as the researcher would do my best to get the participant to agree to speak to the psychological services available. Given that most of the participants were of close relation to myself as the researcher, I also regularly checked that these participants were coping both before and after the interviews. All participants were assigned an interviewer code (a random three-digit number) to ensure that their names did not appear on any transcripts as the best means to try and maintain anonymity. All these steps were implemented with a focus on ensuring that the research report did not bring harm to any

participants, particularly during a precarious and ever-changing environment of the COVID-19 pandemic.

Findings

The findings section starts off by discussing the therapeutics of illness narrative research and then co-construction of narratives in research. This is followed by the section on the COVID-19 illness experience which highlights the symptoms, diagnosis, help-seeking behaviours, and modes of reasoning of the participants interviewed in this research report. The subsequent section titled ‘A case of broken assumptions’ questions the generality of the COVID-19 experience as it discusses a quite severe case of long COVID amongst a female who was in her twenties. Finally, these sections are put together to offer insights into what the data suggests is a ‘COVID illness narrative’.

Therapeutics and Co-construction of Illness Narratives

The following quote comes from interviewee 065 who is in his twenties and is particularly relevant as he had gone through a traumatic COVID-19 experience as he had to look after close family members in what he described as ‘like living in a nursing ward’. At the time of the interview, he was particularly interested in trying to gain an understanding of COVID-19 and its illness experience as sadly he had lost one of his close family members during his own COVID-19 illness experience. This is what he had to say about the interview process as the interview ended:

“I think that just having these types of conversations with people is very useful and beneficial, not just for your research, but in terms of having your own level of understanding. Me speaking about all these things [his COVID-19 experience] is me realising them at the same time [laugh]. These are not the normal type of questions people ask when you talk about COVID, people normally speak about trivial things. I mean, it's debates like are you for or against vaccination and the reasons why and then people are going off as to why they are for it or why they're against it. I feel that topic is dominating the conversation now.

I think that this type of conversation about your experience overall is more insightful and more valuable....”

- (065, October 15, 2021)

This quote is important as it illustrates how the use of narrative research can be a therapeutic tool that allows those involved to rethink, reconceptualise, and piece together their own understanding of COVID-19. The interviewee is provided with a set of questions that allow them to reflect on their own experiences in a way that they perhaps have not done before. The use of open-ended questions also allows for discussion that may lead those involved to experience different perspectives or find solidarity in similarities. For example, three of the interviewees reported getting a rash as a symptom of COVID-19, a symptom that until I conducted interviews, I thought had nothing to do with COVID-19. Conversing about the various similarities, differences and theories with regards to the experiences of having a rash during COVID-19 was only possible with the use of open-ended interviews and provided fertile ground to find solidarity against the uncertainty of the COVID-19 experience. The interview process provides a list of questions however with every interview I conducted the nature of open-ended questions led me to discussions and perspectives that were somewhat unexpected often reshaping my own understanding of COVID-19 and allowing me to reshape how I saw my own experience of COVID-19. I would only expect it to be similar for those participants being interviewed on the other side of the discussion. This points to the therapeutics involved in illness narrative research as the narratives collected are fundamentally co-constructions, they are answers led by specific questions at a snapshot in time. I mention ‘snapshot’ as illness narratives are continuous, always changing when new information is presented, particularly during precarious and rapidly evolving circumstances like the COVID-19 pandemic. In essence, illness narratives research relays the fundamental phenomena in how individuals come to understand their illness, namely, through social interactions. One cannot make sense of their own illness without relation to others, and this illustrates the importance of capturing narratives in narrative research as this allows for others to reconstruct their own understanding of COVID-19. Therefore, this research aims to provide various narratives on COVID-19 to gain a more nuanced comprehension of how the illness has affected the individual and society in multiple facets.

COVID-19 Experience and Modes of Reasoning

A natural starting point of illustrating the illness experience of COVID-19 is by listing the symptoms reported by participants. This is because symptoms make the experience more relatable to others as symptoms are often a common ground for comprehending some of the experience of an illness. For example, listing a headache as a symptom provides somewhat of a common ground for others to understand as they can relate these symptoms to past experiences of having a headache. The severity of symptoms reported varied substantially among the participants. Two participants reported being relatively asymptomatic, the first saying, “I mean, by the time I'd gotten a test, I was pretty much fine. I was never really that sick. It was just like I had like a bit of chest pain the one day, like out of nowhere, and then like a blocked nose and that was pretty much it” (074, September 15, 2021) and the second saying “My initial symptoms were just a burning nose. I actually didn't think I had COVID, I didn't have any of the normal symptoms, I actually had quite a mild case of COVID” (018, December 17, 2021). On the other end of the spectrum, one participant had severe symptoms as she had bad fatigue, difficulty breathing, and coughing so severely that she brought up blood and she was subsequently hospitalised for COVID-19 pneumonia.

Other participants had ‘mild symptoms’ of COVID-19, however, the symptoms reported differed substantially between participants. The most common symptoms shared among the sample were listed as a cough, headache, breathing difficulty, and fatigue, all of which lasted a few days. Other symptoms that were reported in some but not all participants included, diarrhoea, fever, night sweats and sore eyes. Other rarer symptoms included developing a rash (listed by two participants) and an extreme loss of appetite (listed by one participant). The duration and onset of symptoms differed among participants with some experiencing one symptom more intensely than another, some symptoms becoming gradually worse and then fading, some experiencing different symptoms daily, and some are still contending with symptoms of long COVID (i.e., prolonged fatigue after COVID-19). Even though many participants shared common symptoms no two individuals experienced the exact set of symptoms, making the experience of COVID-19 quite different and unique to each person. Another feature of COVID-19 symptoms was uncertainty as symptoms tended to change or individuals were quite worried that they would change suddenly.

A participant who was quite concerned over symptoms that she may have experienced after contracting COVID-19 (since she had dealt with asthma her whole life) added insight into the uncertainty and variance of COVID-19 prognosis when answering the question ‘What normally happens to people with COVID-19?’. She responded by saying:

“Well, it varies, and what I find so strange about this disease is that some people get it and don't know they've got it, they have no symptoms they're not sick, and other people pick up COVID and in three days they are dead. It can infect anyone, and I don't think anyone knows how or if their body is going to be able to manage that disease [COVID-19]...”

- (021, September 10, 2021)

The COVID-19 illness experience is predominantly a story of dealing with uncertainty. This uncertainty existed before any of the participants caught COVID-19 as news about the virus was widely circulated substantially even before the virus entered the country and only intensified through various lockdowns and discoveries of variants. The proliferation of information around COVID-19 has instilled one core chain-complex (events that lead to the disease) around the disease, namely, that it is transmitted through social interaction. All participants within the study provided the chain-complex of social interaction as the reason for catching the virus. For some participants this explanation was easier than others, typically running along with a storyline such as ‘I was in contact with someone who tested positive’, ‘I isolated and then I developed symptoms’, ‘I knew it was most likely COVID-19’. Other participants’ storylines go something along the lines of, ‘I presented with symptoms of COVID-19 but I wasn’t in direct contact with anyone over the past two weeks so I don’t know where I caught the virus, it must have been when I went to the shops’.

Therefore, the COVID-19 illness experience either starts with the individual becoming aware that they have been exposed to someone with COVID-19 and waiting to see if they develop COVID-like symptoms, or the individual develops COVID-like symptoms and reflects on instances of social interaction where they could have possibly caught the virus. Both instances trigger reflection, contemplation, and moralisation to deal with the uncertainty of potentially contracting COVID-19. For example, the individual may ask various questions, ‘Did I wear a mask when seeing the infected person?’, ‘How long ago was the social interaction?’, ‘How likely were they to be contagious?’, ‘Are my symptoms real or am I imagining them because I’m worried?’, ‘Are these COVID-19 symptoms or am I sick with another flu?’, ‘Did I follow COVID-19 protocols?’. The uncertainty around past reflections is also coupled with future contemplations on how the virus will potentially impact the individual’s life. These instances and interactions between the past, present (symptoms), and future uncertainties force the individual to mobilise resources to deal with the potentiality of

being infected with COVID-19. The ability to mobilise resources relies greatly on the individual being able to prove that they have COVID-19, either through a COVID-19 test or diagnosis from a doctor. The importance of this is reflected upon by interviewee 065, who had been caring for close family members with COVID-19 a week before developing COVID-like symptoms:

“Q

Did you go for a COVID-19 test?

A

I did eventually. Even though I knew I had it, I still ended up going for it because of medical aid implications and I needed medical aid to cover me if anything worse happened because if I needed to be hospitalized or things got worse, I would have needed to have a positive test”

- (065, October 15, 2021)

He illustrates the importance of getting a COVID-19 test as he had experienced first-hand the difficulties of obtaining treatment for COVID-19 as this was something that he had experienced when struggling to find oxygen and other supplies for close family members prior to getting COVID-19 himself. One vital aspect of getting resources to deal with COVID-19 is the ability to get a COVID-19 test as it allows the individual to legitimise their experience (i.e., they have proof of having COVID-19). This has implications for receiving medical aid benefits that would pay for medication, which is particularly relevant given the socio-economic status of the group studied. It is important to note that therefore the COVID-19 test provides confirmation for the individual themselves of their diagnosis and legitimises their status to others and in doing so they can mobilise resources to deal with the disease, whether it be social support or medical treatments. It is also important to note that everyone within the study was able to go and get tested for COVID-19 which would indicate that the middle to upper class was particularly well-positioned to rally resources to deal with COVID-19 infections, a factor that could drastically change the illness experience of other socio-economic groups within the country as well as their ability to get resources in the face of COVID-19 infection.

This illustrates the power of diagnosis as a means for legitimising one’s experience of an illness. This is because a medical diagnosis allows an individual to be classified under medical resources, lexicon, and knowledge, and therefore receive approved evidence-based

treatment. However, a diagnosis is not just a label for the medical field to identify and treat ailments but a diagnosis allows oneself to find legitimacy in their experience. In essence, one can confirm that what they are experiencing is indeed a certain illness, they can identify what is wrong. This was of particular importance during COVID-19 given the wide variety of symptoms and its presentation of flu-like symptoms. It was evident that those interviewed most frequently explained their somatic experience of COVID-19 as ‘like-the-flu’. ‘Like-the-flu’ was therefore identified as the most relevant prototype or way of describing what was being experienced in relation to previous experiences of illness. However, rather interestingly quite a few participants described their experience as something like flu but with a mysterious and unexplainable difference to what they had experienced with flu before. For example:

“Some of the symptoms are similar [to flu], for example, a headache and dry, stuffy nose, but it was a different type of feeling ... I could just tell internally that it was not just the normal flu”

- (065, October 15, 2021)

“Actually, having COVID felt quite strange in the sense that it was very different to any other type of sickness or illness that I've had previously in the past. It was the fatigue that I think was one of the most distorting aspects of the illness, just because, like, normally, when you have flu, you feel fatigued, and you feel tired, but not to the point that I had ever experienced when I had COVID”

- (079, December 15, 2021)

The process of legitimising ones experience begins with suspecting that one has contracted COVID-19 (for various reasons, i.e., symptoms, contact, etc), however, one cannot be certain that what they are experiencing is indeed COVID-19 and therefore this requires a positive test result to confirm the actual experience as a COVID-19 one. The process of legitimising ones experience of COVID-19 takes one from a place of uncertainty to certainty. Diagnosis was therefore a vital resource for an individual to confirm that what they were experiencing was truly a result of COVID-19. With a diagnosis, individuals can begin to make sense of their experience and make it relatable. Diagnosis does not just allow the individual to legitimise their experience of COVID-19 but also allows them to ‘prove’ to others that their experience is legitimate.. Through diagnosis, the individual can relate to others what a

‘legitimate’ COVID-19 experience is, for example, stating how the fatigue is so much worse than they have ever experienced with flu previously and in doing this they are able to relate their experience to the social world around them. Their experience becomes a social resource for others to understand how to deal with COVID-19, where to go, what treatments to take and conversely the afflicted individual can receive social support from those within their environment, for example, individuals offering to drop off groceries during their time of isolation. Diagnosis is, therefore, was not just a valuable resource for the individual to understand their own experience of COVID-19 but serves as a means for those around the individual to understand COVID-19 as well, which illustrates the social environment of the COVID-19 experience.

However, getting a diagnosis through a positive COVID-19 test was an area of contention amongst many of those interviewed as the reliability of the test was highly contested. Examples of the contention around COVID-19 are provided below:

“I'd rather get the PCR done, than the rapid test and at least have an accurate result...”

- (065, October 15, 2021)

“I finally booked an appointment and my doctor said that I have COVID even though my test actually came back negative ... I was a bit sceptical...”

- (057, January 7, 2022)

“I was getting both negative reports and positives. So, I didn't know whether I really had it or not, you know what I mean? So, when he said [the doctor] that I had got COVID pneumonia, and he was very determined and very sure... that was the first time I knew for sure what was wrong with me”

- (001, August 9, 2021)

Within the sample, it was apparent that COVID-19 tests had a fair amount of scepticism. However, gaining access to facilities to get tested for COVID-19 did not appear to be an issue within the sample and this is most likely as a result of their class structure. Although, suspicion as to the accuracy of the tests appeared to be an issue. The only time a test provided a sense of

certainty, seemed to be when the result was positive, or individuals were able to get a doctor to diagnose them with COVID-19. Although the COVID-19 test was an area of contention all participants still used these tests as a vital resource for the individual to comprehend their experience and communicate their experience to others. The ability to gain a self-diagnosis in the form of a COVID-19 test somewhat changed the dynamics of the traditional doctor-patient relationship, where the doctor maintains expert power and limits the agency of the patient. The restitution narrative is defined synthetically as when one gives over one's body to medicine to be restored and is not the dominant narrative of those who experienced mild COVID-19. Conversely, a large portion of the sample reported a high level of agency when monitoring their own COVID-19 symptoms and treatments. For example, interviewee 065 speaks about his family's preparedness for COVID-19 infection:

“My interaction with doctors during this experience of getting COVID was very limited.... We knew what vitamins to be taking. We knew that if things got worse, I would be put onto a course of cortisone, and we knew that if my SATs [Oxygen Saturation Levels] dropped below 90, I would probably need some oxygen. It was like we are almost prepared beforehand, and I wouldn't say many thanks to the doctor. You know these things from just living in this time and knowing how other people have gone through it, and what has happened to them, and how they monitored it, and what they did... everyone is a self-appointed COVID expert, and everyone knows something about it and can tell you, ‘Oh, do this, do that, whatever the case may be’, and I think that prepared us more for our experience than what the doctor ever did”

- (065, October 15, 2021)

This quote reflects one of the dominant narratives of the COVID-19 experience found among those interviewed, a narrative of uncertainty disrupting medical knowledge. This is perhaps why some participants showed reluctance to enter the traditional restitution narrative opting to rather exercise their own agency for their treatment. On reflection of this conversation with interviewee 065, I realised that even during my own experience of COVID-19 I was profoundly influenced by the experience of others who had previously contracted COVID-19. Even though these experiences had not happened within my direct network I had heard of them through various family members and friends. These stories relayed treatments and proposed

treatments and experiences of a ‘friend of a friend’ or various treatments and facts that were provided on news outlets and social media. Examples of treatments reported from these types of networks to alleviate symptoms of COVID-19, included the daily use of vitamins (normally b,c,d and zinc), getting plenty of sunshine, drinking energy drinks (such as Powerade), plenty of water and ginger tea, as well as taking various pain killers. Therefore, it is important to note that treatments for COVID-19 were influenced by what I would call the *via-via* network, where one determines their treatment through the information provided by others within their social network.

This greatly impacted professional help-seeking behaviour, as many individuals contacted a doctor as a precautionary measure to check that what they were taking as treatment would be agreed upon by the doctor. One interesting instance of help-seeking behaviour was also presented within the sample, in what I would call *via-via* doctoring, where individuals didn’t seek out professional healthcare but contacted a doctor within their social network to get advice. It must be noted that this would be particularly relevant and perhaps exclusive to the class structure studied as individuals within these classes are more likely to have doctors within their social networks or communities. However, even professional help-seeking experiences could occur in a *via-via* manner with some participants only having telephonic consultations with their doctors or even getting family members to have these consultations on their behalf. Participants within the study had a wide array of resources which increased the ability of the individual to have greater agency over their own treatments for COVID-19.

It is no surprise then that help-seeking behaviour varied greatly with some participants being able to use doctors that were in their social network as resources (*via-via* doctoring), professional help-seeking (in person or online) or in some cases, a mix of these. The Help-seeking experience among the participants varied greatly and the following abstracts are provided to illustrate this:

Via-via Doctoring (doctors within one’s social network):

“We have a neighbour who is a doctor, but he is not my regular doctor. However, I phoned him, and he said that he could treat us from home. When I phoned him, he said immediately that I had COVID. He sent me a WhatsApp to go for the blood tests and that he would give me a report on WhatsApp, you will have my practice number on it. Go and

get the test and at the same time get the medicine on the script. I am treating you for full-blown COVID”

- (091, December 9, 2021)

“The doctor we called was a friend of my dad’s from school. So, we know him personally. So, it was not my normal GP. I never even phoned my normal GP, we didn't even get in contact with her. But that's also purely because my dad knows a doctor so we kind of just phoned him and was like, listen, she caught it, she's not really sick. What do we do kind of thing? If I was a bit sicker, we probably would have done bigger measures like I actually would have gotten to see my GP but it just seemed the easiest because I wasn't really sick kind of thing”

- (018, December 17, 2021)

“Me and my dad were walking around [their estate] and we actually saw our GP and were able to ask her a few things and she was able to recommend a few treatments, like vitamin B, C, D, zinc, disprin, etc. That was the only type of medical treatment that I or my family had...”

- (074, September 15, 2021)

In-person Consultations:

“I then phoned the doctor's room and ask them, well I told him that I had COVID, and I had got my results. “Can I get some medicine’ and they said, ‘Sure come in’ and I said, ‘Well I have got COVID’? They said ‘It’s fine, they have the normal protocols where you had to wait in your car for them [doctors]’. No one was allowed in the waiting area and when the doctor wanted to see me, he called me into his office. It was very strange because no wonder the doctors are getting sick. I just felt that it wasn't very wise for patients that have COVID to get into the rooms...”

- (036, December 16, 2021)

Online Consultations:

“I feel that my GP was not very supportive when I had COVID. She just emailed me saying I had COVID with my results. She wasn't really sympathetic and guiding at all...”

- (043, September 15, 2021)

“I didn't end up going to a doctor, but my mother ended up giving a doctor a phone call and I think it was on a Friday afternoon. The doctor said ‘let him take his medication and the vitamins that I prescribed’...”

- (065, October 15, 2021)

One means of mitigating the uncertainty and risk of going to seek professional healthcare was the utilisation of doctors within the individual's social network by *via-via* doctoring. The experience when seeking professional healthcare seemed to vary to a high degree amongst those I interviewed. This resulted largely from the class position of those interviewed, i.e., being from a middle to upper-class background increases the likelihood that the individual would know a doctor within their social settings or social networks. This is quite different to the traditional doctor-patient relationship as this is not necessarily a professional relationship but a relationship in which the individual is asking for help from those within their social network. The doctor himself has expert knowledge and is trying to help those within their social network, the medical knowledge is not contained like a secret of medicine but rather the doctor is trying to give agency to the patient, making the knowledge accessible and providing comfort to a member within the community.

This said, not everyone within the sample could or did make use of this form of help-seeking behaviour, as other interviewees had in-person, online, or hybrid consultations with doctors. Individuals also received various levels of support from the professional healthcare setting. One of the reasons for the use of *via-via* doctoring by some participants was the need for increased comfort in the face of uncertainty. In this sense, informal settings can provide more comfort as one can speak in lay terms and out of a professional setting, which is particularly useful given the changing and precarious healthcare setting during the COVID-19 pandemic. It is important to illustrate that the use of lay social relationships serves a relatively similar function, individuals can receive comfort from the advice, experiences, and resources of others within their social setting. In this sense, the use of doctors was not the only resource

to deal with the uncertainty and risk associated with COVID-19. One clearly disguisable feature among those participants within the study was the use of close others and their experiences of COVID-19 to make sense of their own experience. While various statistics relayed the risks associated with COVID-19 infection there was an inherent need to make the ‘impersonal’ statistics personal. From the interviews conducted it is evident within the sample that others served as a vital resource in combatting the uncertainty of risk during COVID-19. An example of using others as a resource during the COVID-19 illness experience is provided:

“Q

Do you think that seeing and speaking to people helped more than receiving the available statistics, like a 98% survival rate or something like that?

A

Definitely, because people are real! You can make a stat out of anything, seeing people you know on a personal level and hearing their understanding and speaking to them about it, that makes it real. I think it's closer to home, you can relate to it a lot better than just a stat. The statistics can be scary. You can find very scary or very comforting statistics on COVID, it depends on what you're looking for and how you interpret the figures... Seeing and talking to people who've experienced COVID, particularly those close to you, I find much more beneficial and insightful than just reading about it online or in a news article. It's not real until, as I said, it affects you or the people around you, then it gets really real...”

- (065, October 15, 2021)

Interestingly, the uncertainty that surrounds COVID-19 fostered a situation in which medical and scientific knowledge may not have been the most reliable source of information causing individuals to at least show equal attention to social networks and people around them as a form of authority on COVID-19. This is most likely because everyone is at least acutely aware of what it is like to live within a risk society. Individuals turn to social networks and environments to translate the risk presented in statistical, scientific, and medical knowledge into a more comprehensible and personal understanding, i.e., ‘How will this directly affect me and

those around me?’. A good example of this is when the interviewee speaks about COVID-19 only becoming ‘real’ when you catch it or someone close to you catches the virus. The power of statistical knowledge around COVID-19 plays a pivotal role in how individuals conceptualise the disease and risks associated with it. An important aspect that has influenced the interviewees’ conceptualisations of COVID-19 is their contexts and its ability to make statistical knowledge relatable, as interviewee 065 previously illustrates, to make COVID-19 ‘real’. Therefore, social contexts have profoundly influenced how individuals have come to conceptualise, make sense of, and react to COVID-19.

Therefore, the illness experience of COVID-19 is deeply personal but at the same time very social. Social connections and networks are a resource to make “personal meaning of impersonal statistics” (Jurecic, 2012, p. 23). The statistics that proliferate society around COVID-19 tell the stories of how an individual will most likely fair against the virus. However, it is important to note that the statistics do not relate to the actual experience and can generate statistical panic where “people make the mistake of living their lives by the numbers instead of attending to the dissonance between those numbers and their experiences” (Jurecic, 2012, p. 20). The statistical panic around COVID-19 creates a generalisation of what one’s experience should be which is not always the case. An example of this is provided by one of the interviewees 021 who has dealt with chronic asthma “My chest was getting a bit tight because I am asthmatic and that was one of my big fears about getting COVID-19 in the first place, I didn’t know if my body would be able to cope especially because I was asthmatic...” (021, September 10, 2021). However, she did not experience any difficulties with breathing and was surprised that COVID-19 did not affect her more. Conversely, others also made the error of assuming the experience of others due to statistics on COVID-19. For example, someone who is in their early twenties, who experienced severe side effects of COVID-19 and struggled with recovery for a couple of months but wasn’t given much attention for these long-term symptoms due to the assumption that she would be fine due to her age. There is a dissonance between medical, scientific, and statistical knowledge on COVID-19 and actual lived experiences, a dissonance that one must contend with to comprehend their illness. It appeared that social groups and networks were a fundamental resource in comprehending how the virus would affect an individual.

When experiencing COVID-19 the individual needs to relate their experience to others close to them. The individual needs to make sense of the illness within their local context and in doing so make the experience personal and relatable to others who are in similar positions. In essence, the individual looks to others around them to try and comprehend what might

happen to them. This relates closely to the first paragraph within this section on the co-construction of narratives. These examples of hearing other stories of illness can aid in one's own understanding, particularly when dealing with an illness that is as precarious as COVID-19. Stories of close others aid in the construction of one's own understanding of the illness. Close others make the stories of risk and uncertainty more relatable. The use of speaking to close others is widely documented within the sample of interviews conducted within this research report. Social support and conversation seemed to have been a great resource in dealing with one's experience of COVID-19, this can also be seen with the mention of using vitamins as a form of treatment for COVID-19. All of those interviewed listed this as one of the forms of treatment and interestingly the reason most gave for taking vitamins was that someone close to them advised them to. In the same pattern many other treatments such as the use of ginger tea, energy drinks, moving around to get a bit of exercise, making sure you also rest and get plenty of sunlight, were also mentioned as lay treatments to combat the disease. An example of the influence of close others to treatments taken for COVID-19 is provided in the following extract where the interviewee describes the summary of his treatment and the fact that they took everything both the doctor and those around suggested:

“I took a lot of vitamins and a lot of liquid. I took ginger tea, apparently, that helps. I took whatever everyone told me to... I don't know what helped more than others. I just used it to my advantage. The oximeter, the nebulizer, a steamer. I would phone my mother, she would drop stuff off at the gate, whether it was chicken wraps... oh, I just took everything. Three times a day, breakfast, lunch, and dinner time...”

- (036, December 16, 2021)

It has been demonstrated that the social context had a great influence over individuals' help-seeking behaviours and how they comprehended various aspects of the disease by making it relatable to themselves. However, even though the social context and social networks impact greatly on an individual's experience of COVID-19 there is a dichotomy between being together and being alone. This is largely because of isolation through various lockdowns as well as the isolation period when having COVID-19. One of the most frequent themes for describing their COVID-19 experience is that of isolation. Two interviewees referred to COVID-19 as an 'isolation sickness' with many others referring to feelings of being stigmatized when having

the disease. One interviewee when asked if there is any other term or expression that they would use to describe COVID-19 answered:

“I don't know maybe call it like isolation sickness or it's a very lonely type of virus to contract I would say because I've never contracted something where once you get it you are kind of forced into this little bubble and must stay in this bubble even if you're not feeling ill ... that was that weird thing about it”

- (065, October 15, 2021)

The metaphor of being in your own ‘bubble’ was also frequently used to describe the experience of COVID-19. Jurecic (2012) speaks of ‘cocoon of invulnerability’ which is areas or spaces in which individuals feel as though they are not at risk of sickness, for example, in a peaceful place next to a river with loved ones. However, in relation to the metaphor of COVID-19 forcing individuals into their own bubble, it appears that COVID-19 and its isolating features force the individual into an opposite position, a ‘cocoon of vulnerability’ or a space in which one is forced to acknowledge their own vulnerability to illness in an isolated space. With individuals having to be isolated during the period of COVID-19 infection they are left in a space in which there is a heightened sense of their own vulnerability. In essence, individuals are forced into a space in which they must identify with Sontag’s kingdom of the sick. However, the defining aspect of the COVID-19 experience is that you are isolated from direct social contact. The isolating aspects of COVID-19 are closely linked with the fear of further transmission. The uncertainty around isolation periods was an issue that fuelled stigmatisation. This intersected with the uncertainty in medical and scientific discourse adding more fuel to the stigmatisation fire, i.e., individuals were uncertain if they could still contract the virus even after someone had been in isolation for 14 days. This was particularly relevant for those that caught the disease within the first year of its existence. For these participants, stigmatisation seemed to be an issue that continued even after the 14-day quarantine period had ended. The metaphor of being treated like having ‘the plague’ was cited among a few participants during this period. Stigmatisation was a prevalent issue and was reflected in the interviews of participants. The experience of stigmatisation is illustrated in the following quotes from participants:

“Kind of like you have the plague, to be honest, like stay away from me. Don't come near me even after your 14-day quarantine, everyone treats you differently. ‘Oh, you had it?’, Can you stand over there because just because you've had it once, you must magically still be carrying it three months later...”

- (018, December 17, 2021)

“Well, you know, you don't have your friends around anymore. Like your normal, social life sort of disappears, because obviously, they don't want to get it and you can't blame them. They know I've had it. So, they don't want to be another statistic, and I was fortunate, I suppose because I did come out of the hospital and a lot of people didn't. Uhm, and I suppose their thinking was, I don't want it. Obviously, they had opinions too”

- (001, August 9, 2021)

The isolation period creates a moral dichotomy between wanting to have social contact and some sense of normality and the fear of infecting others. One must think of themselves as well as others. This was relevant during my own experience of COVID-19 as I refused to see anyone until sixteen days after contracting the virus as I was terrified of infecting others and of being blamed for spreading the virus. This phenomenon of ‘felt stigma’ (fear of encountering stigma, not actual incidences of stigmatisation) was shared among those interviewed. The fear of felt stigma seems to be apparent as you don't want to be ‘the one’ who gives COVID-19 to others. Interviewee 036 shared a similar experience when catching COVID-19 for the second time as his boss told him that according to the labour law he needed to go back to work after a seven-day period. However, he did not go into work over the fear of being ‘blamed’ or ‘victimised’:

“Yes, I didn't want to go to work because the previous time that I had COVID had been back in July, and it felt like I was victimized; ‘Word on the Street was [their name] bought COVID to the office’. Obviously, I would not deliberately take my sickness or my flu to work. Obviously, I hadn't known about it, but then apparently, three days later, one of my colleagues fell ill with COVID. That's why I didn't want to take the

chance to go back to work because I didn't want to get victimized and blamed that I am the spreader of COVID”

- (036, December 16, 2021)

However, fear of felt stigma was not the only type of stigma found amongst those interviewed. Interviewee 091 used ‘conscious biases’ as another way of her describing the COVID-19 experience. When she was asked to elaborate on what they meant by ‘conscious biases’ she responded by providing two experiences of enacted stigma (actual incidences or experience of stigmatisation) after isolating for their fourteen-day period:

“When we went for a walk. We just went up the road, it's literally 200 meters, it's a not lot. One of our neighbours wanted to come out and speak to us and even though we were on the other side of the road with all our masks on, but still his family actually said to him, ‘No, you don't go out there and say hello at all, they've got COVID’.

...

That was the one and the other one, I went to a beautician... We were standing on the side and this woman gave me filthy looks because we were talking about it [her experience of COVID-19]. I have not felt that at work, I have not felt it amongst friends and family. But certainly, up there in the bigger scheme of things, definitely!

...

From my experience, you're completely isolated and alienated from people you don't expect if from at all. That's hard. It's like you're walking around, and you've got a virus that is showing all over your body almost to use the old expression, like leprosy, and everybody can see it, and that to me, it's not acceptable. It's not right. If everybody is following protocol. We're doing what you're supposed to be doing, we've still got to live, the human race will continue. We can't do that with each other”

- (091, December 9, 2021)

Stigmatisation has had a definite interplay between uncertainty, medical discourse, and public policy on isolation. The experience of both felt and enacted stigma because of COVID-19 infection points towards one of the disease's longer-lasting effects. In the sense, that one can still encounter adverse experiences because of COVID-19 infection long after this disease is gone. These effects are not just social and environmental as individuals may still experience long-lasting illness because of COVID-19. It must be acknowledged that many of the participants within the sample claimed that their illness experience of COVID-19 lasted longer than the assumed fourteen-day period. Various interviewees reported that they or others had or are continuing to experience long-term COVID-19 effects. The most frequently listed long-term COVID-19 symptoms were of 'brain fog' or difficulty concentrating for a significant period after COVID-19, which was described by one of the interviewees as "porridge brain" (091, December 9, 2021). Another long-term symptom of COVID-19 was its long-term effects on an individual's taste and smell. These effects varied from a dislike towards foods previously enjoyed, to a similar experience towards fragrances and colognes. Another frequently quoted long-term symptom was that of fatigue, an experience which is described something along the lines of - "I still experienced the fatigue when walking upstairs, I get quite tired easily. That hasn't gone away..." (057, January 7, 2022).

While individuals have cited various long-term symptoms of COVID-19 such as lack of concentration, long-lasting loss of taste and smell, and long-lasting fatigue some individuals don't describe their long-term effects of COVID-19 as 'long-COVID' but rather that COVID-19 had made previous conditions hard to manage going forward. An example of this is provided by an interviewee "My asthma has definitely not been right. My asthma control has been more difficult as a long term effect" (091, December 9, 2021). The experience of long-COVID within this sample has been extremely diverse and varied. This variability of long-COVID symptoms, possesses issues for those having to live with them as 1) They can't get recognition through a legitimate diagnosis and 2) It is very difficult to relay the effects of their symptoms to others who don't have them. Long COVID then exacerbates the uncertainty around COVID-19 and makes it harder to comprehend the illness experience as those afflicted, particularly because long COVID is contested and handled with a pinch of scepticism amongst medical discourses.

Confusion over the adverse effects of COVID-19 does not just rest within a contested long COVID framework but with the general social context of a pandemic. The social context of a pandemic ensures that everyone is experiencing the effects of COVID-19 even if it is not a direct infection. This is echoed by many metaphors provided by participants when referring to COVID-19 in terms such as "fear-inducer" (057, January 7, 2022), "a horror story" (091,

December 9, 2021), “world changer” (091, December 9, 2021), and “boarder-closer or “life-stopper” (096, December 20, 2021). These metaphors offer insight into the rapidly changing world during the COVID-19 pandemic. There is undoubtedly uncertainty around the COVID-19 illness, however, there is perhaps even more uncertainty around the interaction of the rapid changes to the social context during COVID-19 and its effect on individuals’ psycho-social traumas. There is an apparent compounding effect of the social-psychological uncertainty and uncertainty around the COVID-19 illness that makes the experience of COVID-19 even more complex. A few participants highlighted an idiom of distress for the compounding effects of uncertainty and risk around COVID-19 was found within the sample with the phrase ‘back-to-a-new-normal’. This phrase is a cultural expression of what I would describe as fear over having to live in uncertain times where risk cannot be calculated, a fear of having to live with a heightened acknowledgement for the risk society and the fragility of health and wellbeing.

The aim of this section on the illness experience of COVID-19 examines the various aspect of the experience such as diagnosis, symptoms, treatments, help-seeking, service utilization, modes of reasoning, and the metaphoric nature of the illness, among a ‘presumable’ homogenous and small group. While many participants share commonalities with their experience of COVID-19 it is important to note that nearly all the stories told were different. The only common themes identified among this group was that of uncertainty, of being able to seek medical care and diagnosis, and that everyone’s experience was profoundly impacted by the social context and networks in which they found themselves. However, I would be hesitant to generalise any experiences of COVID-19 after listening to participants’ stories. The COVID-19 illness experience is complex and multifaceted, interweaving with many biological, medical, scientific, social, environmental, and structural factors, which makes assumptions dangerously misleading. There needs to be more ethnographic and illness narrative work around COVID-19 if we are to begin to understand this complexity and how individuals within society comprehend, reacted to, and will be impacted going forward. The danger of assumptions regarding COVID-19 is illustrated in the next section.

A Case of Broken Assumptions

I title this section ‘A Case of Broken Assumptions’ as it goes against the general assumptions of COVID-19, particularly the assumptions that if you are young, have no co-morbidities, are relatively healthy, have caught COVID-19 before and dealt with it well, you would most likely be fine and recover quickly. These assumptions did not only reflect the viewpoints of interviewee 043 but for me as well. Listening to the narrative told by her greatly impacted my

own assumptions of COVID-19. It reinforced the notion of the risk society, that even though I had recovered from COVID-19, I was not necessarily safe. It made me reflect on perhaps how little knowledge we have about the COVID-19 experience and how accurately we could demonstrate its narratives given its sheer variability. It illustrated the importance of in-depth, ethnographic, and narrative work to illustrate how varied the experience of COVID-19 is. The importance of giving voice to the variability of COVID-19 as a means of making the experience more relatable and in doing so allow for greater comprehension and understanding around the COVID-19 pandemic. This is particularly important for the experiences of COVID-19 which are confusing, contested, and not well understood, such as in the case of interviewee 043.

Interview 043 is in her mid-twenties and her illness experience of COVID-19 first occurred during the first wave of infection within South Africa. She describes her first experience of COVID-19 as - “a little cold” (043, September 15, 2021). She reports no long-term effects from her first infection of COVID-19 but subsequently got re-infected with COVID-19 during the third wave of infections within South Africa which was a more severe experience than the first. Her experience of the second infection begun as such:

“Because the last time I had COVID, I was fine, and because I've been exercising and being healthy, and because I'm young, I thought, ‘oh, no, If I get it again it would be really chilled’. So, I was not stressed at all but then I started having symptoms...

...

I was feeling super nauseous, vomiting and the cough was like nothing I had ever experienced before. It was even worse than having bronchitis. I don't know how to explain the cough, ... it was just in another world. It was scary coughing [laughter]. I had a bad cough, fatigue, bad headaches... and they aren't just like migraines. I don't even know how to explain it. All the symptoms just weren't normal, they were completely new and different to anything I've ever experienced”

- (043, September 15, 2021)

Although she was not hospitalised for COVID-19 and would have been classed as having a mild case of COVID-19 it is evident that her second infection was significantly worse than her first. However, her experience of the second infection did not end within a fourteen-day period as she recounted feeling horrible after their isolation period and consulting both

homoeopathic and biomedical practices to try and mitigate the longer lasting effects of COVID-19. This experience is provided in the words of the interviewee:

“After the two weeks of being in isolation, I slowly started easing back into my life and then even a month after, I was still feeling absolutely horrible. So, I went to a homoeopathic doctor, and she said that I had long COVID... because I still have fatigue, brain fog, and I struggled to concentrate. The fatigue is the worst thing. I think it's so hard to explain to people because it's not something you can see or test for... So, it's hard to explain it, even to my parents, they will just be like, ‘aww, just go have a nap and you'll feel better’, but I am constantly feeling heavy and tired ... and now... I went back to the doctor because I had chest pain and a high heart rate. The doctor said I must go to a cardiologist. So then last week, Friday, I went to a cardiologist, and he said that the high heart rate can't be explained by doctors, it's so weird, but it's just a waiting game...”

- (043, September 15, 2021)

The most frequent theme during this interview around the experiences of long-COVID was that of frustration, frustration at the way they were feeling, frustration with not having answers, and frustration she could not relate her experience to others, it was profoundly different to others’ experience of COVID-19. Insight is provided to illustrate the frustration she felt when having to contend with long COVID in the following extracts of her response to the question, - ‘How would you describe your experience of COVID?’:

“Frustrating [laugh].... I think just because there is so little known about it, doctors can't give a definite answer, and every doctor has a different opinion. It's just frustrating [laughing]. Like, I wish there was a pill you could take for the long-term effects

...

I think the hardest thing is to explain it [long-COVID] to other people because it's not just like a test to see you know, what's wrong with you? I think it has a lot of mental aspects, like brain fog, fatigue and anxiety.

It's all mental, and I think that's where there is the most stigma and it's so hard to explain because people can't just look at you and see that. With a cough, they can hear, 'Oh she is sick, I feel bad for you', but with the long-term effects, I don't gain that much sympathy [laughing]

...

I hate it [COVID], and I'm frustrated because of the long-term effects because there's not enough research on it yet. Everyone's just focusing on how you feel during it, but actually, I feel worse after it. I think I'm frustrated about that, and how my body's feeling. I'm also just frustrated in general..."

- (043, September 15, 2021)

The illness narrative of this interviewee reflects one of great uncertainty of symptoms, prognosis, treatment, and of others acknowledging the legitimacy of the experience. It runs along the same lines as those postulated by Frank's (1997b) concept of the remission society in the sense that the individual is left in between the kingdoms of the well and the sick. They have been deemed to have recovered from the COVID-19 infection but are not able to be resituated to their former self due to the adverse effects of the infection. This would indicate the importance of future study around those experiencing long term effects and an acknowledgement that mild COVID-19 diagnosis has a great potential to be misleading. This uncertainty between health and illness is prevalent during the COVID-19 pandemic. This is indicated among the interviewees as they mentioned frequently the various uncertainties of the pandemic, ranging from economic to psychological effects. Uncertainty appears to be the dominant narrative found amongst those interviewed. This has been reflected in the frequent use of the term 'back to a new normal' which can be viewed as an idiom of distress. There is no doubt that many are dealing with the grief of lost loved ones that will sit with them for a long time. Others are also dealing with time lost with loved ones due to the various lockdowns and isolating procedures over the course of the pandemic. Not only can the actual illness experience of COVID-19 last on a longer continuity but the psychological effects of living through a pandemic do also. The illness narratives around COVID-19 have had a profound effect on individuals' life course and their narratives, and this should not be ignored going forward. Interviewee 018 (in her twenties), who experienced a relatively asymptomatic experience of COVID-19 and would be expected to therefore have no long-term effects because of COVID-19 provides a reflection on this:

“I’m sure like every other pandemic that has ever occurred in history, we will eventually get over this but the mental effects that we’ve all suffered from this whole being boxed-in, being afraid of our neighbours, being isolated for this long. I do think is going to stay with our generation We’re going to interact differently with each other. I think even after it finishes even after... if life goes back to normal, I think we will always have that little bit of anxiety, even if we’re not aware of it. It will be there, but I do think it’s going to affect us long term...”

- (018, December 17, 2021)

There appears to be a correlation between illness as continuity and COVID-19 narratives. For those who can recover from COVID-19 infection, there is still continuity in the fact that their social context is still situated within a pandemic, i.e., the risk of reinfection still exists. For others, the adverse effects of COVID-19 infection continue and manifest in ‘weird’ and ‘strange’ ways with unresolved comprehension for the impact of COVID-19 on their health and life going forward. There is a potential continuity of illness outside of COVID-19 infection for those who experience various adverse effects because of living with fearful, traumatic, and uncertain circumstances such as isolation, grief, and bereavement as a result of the COVID-19 pandemic. What is classified as mild-COVID-19 infection needs to be future contextualised to ensure that the word ‘mild’ does not downplay the actual experience. Many are continuing to live with a heightened acknowledgement of the risk society, which could potentially have an impact on an individual’s health and wellbeing over a great temporality or life course. The discussion of results would hint towards the value of treating COVID-19 illness narratives as a continuity rather than merely a biographical disruption. The results from this sample indicate an extreme diversity of experience in what would potentially be expected to be a homogenous sample. This points towards the danger of generalising the COVID-19 experience and particularly its impact on the individual. This would also point to the importance of work such as illness narratives around COVID-19 as a means of gaining a more holistic and complete understanding of the impact of COVID-19.

COVID-19 Illness Narratives

This discussion of results has indicated a variety of COVID-19 illness experiences with regards to diagnosis, symptoms, treatments, help-seeking, service utilization and modes of reasoning, among a 'presumable' homogenous and small group. The narratives told among those participants predominantly relay stories of risk and uncertainty. The themes of risk and uncertainty are entangled in almost every aspect of the COVID-19 illness experience. The onset of symptoms is precarious, novel, and ever-changing from individual to individual. The validity of COVID-19 tests is treated with at least a pinch of scepticism. Health-seeking behaviour, service utilisation and treatments are influenced by access to both medical and social knowledge of the pandemic. Medical and social knowledge both perpetuate the theme of uncertainty, as the soteriological nature of medicine is disrupted causing individuals to seek social resources as a means of combatting the uncertainty surrounding COVID-19. However, the social resources available are dichotomous, on the one hand providing support with various lay theories, check-ups, and deliveries, on the other hand, the individual is isolated and stigmatized for social interaction. Participants within the study experienced great agency over the course of the pandemic as they were able to pull from both resources of information (medical or social) but did not have to rely solely on one or the other. The COVID-19 narratives are stories told of continuity, for some these are the continuous physical and psychological effects that remain after COVID-19, for others even the indirect effects of living through a pandemic are present. This research would indicate that no one single narrative of COVID-19 exists but rather a plethora of different experiences of dealing with various uncertainties and risks associated with COVID-19. Therefore, it is important that the narratives told around COVID-19 avoid broader generalisations but rather delves into the in-depth and nuanced social nature of the illness.

Conclusions

The research paper provided insight into a wide array of experiences in relation to COVID-19, namely, diagnosis, symptoms, treatment, help-seeking behaviour, service utilisation, and modes of reasoning. Individuals experienced a wide array of uncertainty with regards to the legitimacy of COVID-19 tests, regardless of them being rapid or PCR tests. However, diagnosis of COVID-19 appears to be a valuable resource for an individual conferring their experience as a COVID-19 one. This is largely due to the prototype of COVID-19 being 'like the flu'. However, the experience of COVID-19 was often described as a 'severe' or 'more intense' flu, leaving individuals confused and uncertain as to whether it was COVID-19 or the flu. A dichotomy

emerged between COVID-19 being like the flu and it being unlike any experience before. Hence, the value of diagnosis for conferring their experience of COVID-19.

Those interviewed experienced an extreme diversity of symptoms, ranging from asymptomatic infection to severe infection with hospitalization. The variety of symptoms and their prognosis appear to have been a big issue regarding the uncertainty amongst those interviewed. The fear and anxiety of not knowing what would happen from day-to-day has been identified as a prominent feature of the COVID-19 experience. Treatments varied greatly, except for the uptake of vitamins which was mentioned by all of those interviewed. Treatments varied depending on two big factors, namely, the advice from the doctor as well as advice from lay individuals within their social context. These both served as a resource for individuals in determining what medication to take or what counted as treatment. There was a difference in the traditional doctor-patient relationship regarding the amount of agency the participants had over their own treatment as well as the increased importance placed on lay knowledge.

Help-seeking behaviour also echoed the theme of uncertainty as many interviewees experienced different interactions when receiving professional healthcare for COVID-19. These experiences ranged from individuals never speaking directly to a doctor to individuals being able to go for a physical consultation. Of particular interest was the use of a *via-via* doctoring system in which individuals within the sample were able to gain advice from doctors within their social networks. This is most likely a result of the class system from which the sample was drawn. Of importance was also the experience of others within their social system, which served as a resource for understanding COVID-19. This was delivered through lay word of mouth. It was also indicated that this class did not struggle with access to information and was well informed regarding COVID-19. Social networks and culture among those interviewed appeared to be of great resource in dealing with the COVID-19 experience.

Illness narratives and the use of the MINI (Groleau et al., 2006) were able to provide metaphors, stigmas, and idioms of distress that aided in the understanding of COVID-19. Incidences of both enacted and felt stigma were found within the sample. Stigmatization presented as a constraint for participants to return to their normal lives post COVID-19 infection. Various metaphors were identified to describe the experience of COVID-19, such as, 'fear-inducer', 'isolation-sickness', 'like having leprosy', 'being forced into a bubble', 'a horror story', 'like having porridge brain', and 'not being able to put one foot in front of the other'. Interviewees expressed experiences and feelings of both enacted and felt stigma because of COVID-19. The most prevalent idiom of distress used was that of getting 'back to a new

normal' which appeared to relay frustration, fear, and anxiety towards the current situation of not being able to calculate the risks of everyday life.

Although for some the physical experience of COVID-19 was reported in what can be classed as a disruption which would match the 'expectations' of a case of mild COVID-19 with recovery occurring within two weeks. Six out of the eleven interviewees indicated long-COVID symptoms that lasted longer than this period, with some still dealing with long-term symptoms of COVID-19. This would indicate that COVID-19 cannot be assumed to be a biographical disruption as the illness experience could potentially last for a longer temporal period. Even if individuals can find treatments for the long-term symptoms, or these symptoms resolve themselves, there is still the prevalent issue with regards to burred lines of health and illness while living through the pandemic. Individuals who experience the illness and recover with little issue still return to a context in which the pandemic is occurring and still must deal with potential risks, uncertainties, and anxieties that are present. Many of the interviewees, regardless of the severity of their own experience of COVID-19, are concerned both for themselves as well as others regarding negative psychological outcomes because of living through the COVID-19 pandemic. Many of these factors would suggest experiences close to those often relayed within literature around chronic illness and hence the mention of a variety of authors who situate their work on chronic disease within the literature review. This would suggest that the distinctions between disease (as a biomedical construct) and illness (as a subjective experience) have somewhat been upset during the COVID-19 pandemic. While disease as a biomedical construct is a useful resource to aid in ones comprehension of COVID-19 it is evident that the experience and adverse effects of COVID-19 manifest far out of this framework often accompanied by a high degree of uncertainty. Therefore, the distinction between disease and illness with regard to COVID-19 is not clear and often overlapping. This discussion would indicate the importance of examining COVID-19 as a continuity or ongoing phenomenon in which the impact is not adequately understood.

The research indicates that a white middle to upper class may have a different experience of COVID-19 given their ability to mobilise resources. In particular, the ability to gain a diagnosis allowed this group to legitimise their experience, i.e., they could confirm to themselves and to others that they had COVID-19 and in doing so could shape their own understanding in relation to past experiences. Social groups which do not have the resources to get a diagnosis would struggle to relate their experience as a COVID-19 one. The research indicates that the white middle to upper class had greater agency in the doctor-patient relationship than is traditionally expected as they were able to mobilise various resources with

a high degree of autonomy, such as via-via networking, where doctors were companions giving aid rather than professional experts as seen in their traditional roles. Increased agency rested on the ability to mobilise various resources (medical/scientific and social) which gave them access to information, treatments, and support. These common factors among those studied could be linked to structural and systemic inequalities as illustrated with theory on critical whiteness studies and the prevailing system of racial inequality in post-apartheid. Therefore, race and class are fundamental factors that influence COVID-19 diagnosis and its legitimacy, resource acquisition and level agency, and ultimately the overall comprehension and experience of COVID-19.

This research has illustrated the usefulness of illness narratives as a tool for establishing a more nuanced understanding of COVID-19. The MINI was a valuable tool for assessing the conceptualisation of COVID-19 by participants and the narratives derived from the questions were able to illustrate the social nature of COVID-19. However, there was a limitation with regards to analysing the social complexities of COVID-19 illness. Therefore, a framework needs to be developed to analyse the reciprocal interactions between the social world and its influence on the construction of one's understanding of COVID-19. The research indicates the importance of the social world on how individuals conceptualise and make sense of their experience of COVID-19. It emphasises the importance of investigating more in-depth and personal experiences of COVID-19 to gain a more nuanced and accurate understanding of the effects that it has on the individual. Narratives that relay the social dynamics of COVID-19 need to be further researched. This research illustrates the value of illness narratives as a qualitative research tool for gaining an understanding of the wide array of effects on the individual and should be utilised for further investigation on COVID-19.

Questions for Future Research

- 1) Could the MINI be better adapted to epidemic/pandemic contexts?
 - I found the MINI to be a good foundational research tool. It provided a good overall structure to interviews and was a good aid to spark conversation and topical points. I found it to have a logical structure and compartmentalised the experience of COVID-19 well. However, I found the MINI to be a bit limiting with regards to understanding and/or capturing the contexts of the COVID-19 pandemic. Many of these aspects found within interviews occurred when the interview went 'off script' emphasising the importance of open-ended interviews. However, I wonder if the

MINI could have an adapted section in the future that could aid in contextualising the environments and contexts of infectious diseases?

- 2) Are there sociodemographic factors (particularly relating to gender and age) that influence(d) individuals' experience of COVID-19, and if so, how?
 - This study did not find any differences between age and gender; however, this is most likely a result of the study's limitations. For example, the use of interviewer codes helped in attempting to maintain the anonymity of the participants but made the identification of gender difficult. The study also found it hard to get older participants involved, making it harder to draw distinctions based on age. These sociodemographic factors could have influenced the experience of COVID-19 and should be investigated further.
- 3) How important are statistics in shaping individual conceptualisations of an illness during epidemic/pandemic contexts?
 - Although the study emphasises the need for individuals to make sense of statistical data around disease and illness, it is evident that statistical data heavily influenced conceptualisations of COVID-19. Therefore, it would be useful to undergo an examination of how statistical data has shaped individuals' conceptualisations and responses during the COVID-19 pandemic.
- 4) How influential is media in relaying personal experiences of illness?
 - This study did not particularly recognise the influence of media (including social media) on individuals' conceptualisation of COVID-19 illness. It must be reflected that media can also relay personal stories of illness. Examination of how media has portrayed personal or collective illness experience of COVID-19 over the course of the pandemic could be a fruitful area of enquiry.

Appendix A: Adapted Interview Questions

These questions have been adapted from the McGill Illness Narrative Interview (MINI). These questions entail a semi-structured interview process. It is important to note that questions of the interview are open-ended and therefore some questions will only be used if the interviewee has not specifically referred to it previously. Therefore, these questions act as a guide for the interview process, but some questions may be left out or adapted during the course of the interview.

Section 1: Initial Illness Narratives

1. When did you first experience COVID-19 or first experience difficulties with COVID-19?
 - a. And then? And then? (Keep narrative going if possible)
2. What happened during the time you had COVID-19?
 - a. Did anything else happen?
3. If you went to see a doctor/healer or both, could you tell me about your visit(s)?
 - a. How did it make you feel?
 - b. What happened after the visit?
4. Were you hospitalized for COVID-19?
 - a. If yes, how was your experience, what happened, did this affect you after you returned home?
5. Did you have any tests or treatment done for COVID-19?
 - a. What was your experience of the tests/treatment?

Section 2: Explanatory Models

6. Do you have any other term or expression that could possibly describe COVID-19?
7. What do you believe caused you to get COVID-19?
 - a. Any other causes that you can think of?
8. What happened inside your body when you had COVID-19?
9. Is there anything happening in your family, at work or social life that could help explain COVID-19?
 - a. If yes, can you tell me how it explains COVID-19?
10. What does COVID-19 mean to you?
11. What usually happens to people with COVID-19?
12. How do other people react to someone with COVID-19?
13. Do you believe that COVID-19 is somehow related to another specific event in your life?
 - a. If yes, could you please explain why it is linked?

Section 3: Help Seeking and Service Utilization

14. Were you able to physically see a doctor/healer or did you get treated virtually (telephonically, online, etc)?
15. Did your doctor/healer give you treatments, medicines, or recommendations to follow with regards to COVID-19?

- a. How did you deal with these?
 - b. How did social distancing effect you during COVID-19?
 - c. Where you able to follow these?
16. What made the treatment work well/poorly?
 17. Did you expect any treatments that you did not receive?
 18. Are there any treatments, therapies or help that you still want to receive?

Section 4: Impact of the Illness

19. How has COVID-19 changed the way you live?
20. How COVID-19 changed the way you think/feel about yourself?
21. How has COVID-19 changed the way you look at life?
22. Has COVID-19 changed the ways others see you?
 - a. If yes, how?
23. Has COVID-19 change your relationships with others?
24. What has helped you deal with COVID-19?
25. Have spiritual, religious or faith practices helped you in dealing with the impact of COVID-19?
 - a. If yes, how?
26. What do you think has been the greatest impact of COVID-19?
27. How has COVID-19 impacted your community or neighbourhood?
28. Do you believe COVID-19 has changed South Africa?
 - a. If yes, how?
 - b. Why has it changed South Africa?
29. Do you believe COVID-19 has changed the world?
 - a. If yes, how?
 - b. Why has it changed the world?
30. Is there anything else you would like to add

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