

**Experiences and Challenges Faced by Adult Learners with
'Hidden' Disabilities in Higher Education**

By

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DEDICATION

To my husband, Zack, who always believed in me...

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ABSTRACT

The purpose of this study is to gain insight into the lives of chronically ill adult students as they navigate their way through higher education. Chronic illness can potentially limit the performance of adult learners in study-related functions such as concentrating, reading, writing and conversing, as well as restricting their participation in learning situations. The issues associated with living and studying when chronically ill are convoluted by a myriad of interlinking psychological, cultural, social and historical aspects. These aspects influence a chronically ill student's management and subsequent success or non success in a higher education context. The complexities of a 'hidden' disability, which in the context of this study refer to chronic illnesses, in particular, autoimmune illnesses, combined with the challenges of being an adult learner in a higher education environment, creates a field of research that needs to be explored in greater detail in order to better serve this 'hidden' population.

In order to conceptualise and provide a way of understanding the experiences and challenges of adult learners with „hidden“ disabilities within an educational context, three models or theories, the interactional disability model, Jarvis's learning theory and the Dialogical Self Theory were used in order to provide an amalgamated approach and a more comprehensive, integrated theoretical framework. A narrative approach and qualitative style was chosen, underpinned by the assumptions of an interpretive paradigm. Four participants, with the researcher making up the fifth, were selected by snowball sampling. With each participant, an in-depth narrative interview was conducted.

Using thematic analysis, the narrative interviews were analysed and the predominant themes and patterns were identified. Significant themes such as illness management, learning management, relationships, disclosures and identity are illuminated and expounded upon by using the above theoretical frameworks. This analysis and discussion helps to show how complex, interactional and multifaceted the life-worlds of adult learners with „hidden“ disabilities in higher education can be and the multitude of barriers they face. It also shows that the self-positions that adult learners adopt play a crucial role in how these students engage with these barriers. The dissertation concludes with a synthesised discussion on the findings and relevant literature, in light of the initial research questions, and on the implications, insights, recommendations and limitations based on the study's findings.

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CHAPTER 1: INTRODUCTION

1.1 Introduction

Disability comes in many different forms. Traditionally, when one thinks of disability, people with static, unchanging physical impairments such as blindness, paraplegia and other visible manifestations come to mind, but chronic illness can also be seen as a disability (Davis, 2005; Fitzgerald & Paterson, 1995; Hammer, Werth & Dunn, 2009; Jung, 2002; Laidmäe, 2012; Royster & Marshall, 2008; Shiu, 2001; Valeras, 2010; Wendall, 2001; Williams, 1999). This type of disability can remain in the shadows, hidden by the smiles of seemingly healthy people who on a daily basis have to face the challenges of living with a chronic illness (Wendall, 2001). Wendall (2001) explains that “chronic illness frequently involves pain, fatigue, dizziness, nausea, weakness, depression, and/or other impairments that are hard to ignore” (p. 23). The impact of chronic illness on a person’s functionality and participation in life is erratic and constantly shifting, but is nonetheless disabling (Fitzgerald & Paterson, 1995; Hammer et al., 2009; Jung, 2002; Royster & Marshall, 2008; Shiu, 2001; Valeras, 2010; Wendall, 2001).

Academic success can be adversely affected by the psychosocial stressors and barriers experienced by students with disabilities in higher education (Howell, 2006). This is compounded by additional barriers and stressors associated with being an adult learner in higher education such as work commitments, family obligations and other adult responsibilities (Buchler, Castle, Osman & Walters, 2004; O’Donnell & Tobbell, 2007). Considering the impact that ill health can have on a person’s life (Charmaz, 1983; Fitzgerald & Paterson, 1995; Jung, 2002; Royster & Marshall, 2008; Shiu, 2001; Valeras, 2010; Wendall, 2001), one can deduce that chronic illness can be a major barrier to success in higher education. The complexities of a 'hidden' disability combined with the challenges of being an adult learner in a higher education environment create a field of research that needs to be explored in greater detail in order to better serve this 'hidden' population.

1.2 Background

Research, worldwide, shows that living with chronic illness is fraught with difficulties ranging from trying to cope with ill health on a day to day basis, to complexities in

management of interpersonal relationships, to much wider psychosocial and cultural issues (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Laidmäe, 2012; Shiu, 2001; Valeras, 2010; Wendall, 2001). Within an educational context, chronic illness can negatively affect a person's growth as a student, their academic prowess, social relationships and sense of worth (Hammer et al., 2009; Jung, 2002; Olney & Brockelman, 2003; Royster & Marshall, 2008; Sierra-Zarella, 2005; Vavouraki, Panagiaris & Sflomos, 2009). The above literature, which is explored in more detail in chapter two, provides compelling evidence of how potentially disabling a chronic illness can be.

The chronically ill appear to grapple with many of the same barriers, constraints and hardships that have been identified as sources of disablement in definitions of disability. The World Health Organisation's explanation of disability seems to encompass, in its recognition of social barriers, both chronic illness and physical impairments as limiting a person's ability to participate and function on multiple levels:

Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. (World Health Organisation, 2013)

Wendall (2001) adds that "recognition of impairment is crucial to the inclusion of people with chronic illness in disability politics...they cannot be accommodated if they are not acknowledged and discussed openly" (p. 23).

The education of persons with disabilities has been recognised as a priority throughout most of the world. The United Nation's *Convention on the Rights of Persons with Disabilities* was developed as a "comprehensive framework to protect and promote the rights of persons with disabilities" (United Nations, 2011, p. 13). The convention emphasises that an inclusive education system needs to be developed which can "provide for reasonable accommodation

of the individual's requirements and ensure that persons with disabilities are provided with „effective individualized support measures“ to maximize their academic and social development” (United Nations, 2011, p.16). The convention stresses that in order to ensure the independence of and social inclusion of all people with disabilities, equal access to education is an essential and fundamental requirement.

The provision and improvement of educational opportunities for persons with disabilities in South Africa has been earmarked as a special concern. The South African Department of Education (DoE) and the Department of Higher Education and Training (DHET) have tried, through the *White Paper 6* and the *White Paper for Post-School Education and Training*, to address the issues surrounding the education of people with disabilities, but at present, “there is no national policy on disability to guide education and training institutions in the post-school domain” (DHET, 2013, p. 45). Although the *White Paper 6* (DoE, 2001) provides a guide for inclusive education in order to address disability in education, its focus is mainly oriented towards schooling. One of the aims of the *White Paper on Post-School Education and Training* (DHET, 2013) is to redress past injustices and ensure equal participation and opportunities for post-school students with disabilities, but, as the document notes, due to lack of research and inadequate information about these students, the development and implementation of an effective policy is proving to be difficult. It contends that:

Accurate and up-to-date data on the number of post-school students with disabilities is not available. It is essential to achieve a fuller understanding of the number of people with disabilities, and the types of disabilities of people within the post-school system. It is recognised that people with disabilities do not always disclose their disabilities, and this must be addressed. (DHET, 2013, pg. 45)

This statement points to some of the inherent problems around disability, disclosure and its impact on accurate research. Another pertinent issue identified within the *White Paper on Post-School Education and Training* (DHET, 2013) is the need for a wider, more encompassing definition of disability that includes and represents the myriad of disabilities that are present in our society. This approach supports the focus of the present study on hidden disabilities related to chronic illnesses. The Department of Social Development's *Draft First Periodic Country Report on the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)* (Government Gazette 38802, Notice 445, 18 May

2015) touches on all of the above issues and highlights the importance of effective policy implementation in order to effectively integrate and accommodate those with disabilities within the educational context.

1.3 Rationale

Given this context, the issue of „hidden“ disabilities is an important but neglected topic which requires scholarly attention. Universities and other higher education institutions, in light of the above legislation, have a legal and ethical responsibility to provide access and support to students with disabilities, but these resources can only be accessed if the students disclose their disability. Disclosure and non-disclosure are enormously complex and thus impact on whether students with „hidden“ disabilities will seek out and receive the help they require.

„Hidden“ disabilities in higher education have received some attention internationally, but the scholarship on this phenomenon is still at a fledgling stage. There is a small body of research that focuses on, or at least features, chronic illness as a „hidden“ disability within a higher education context, but it does not concentrate on adult learners in particular (Hammer et al., 2009; Jung, 2002; Olney & Brockelman, 2003; Royster & Marshall, 2008; Sierra-Zarella, 2005; Vavouraki et al., 2009). There is research on adult learners in higher education (Buchler et al., 2004; Howell, 2006; O'Donnell & Tobbell, 2007), learners with disabilities in higher education (Fuller, Bradley & Healy, 2004; Healy, Fuller, Bradley & Hall, 2006; Howell, 2006), adult learners with disabilities in other education contexts and research on adult learning theories utilised in learning about chronic illness (Baumgartner, 2011; Chappell, 2013; Clark, 2006; Francis, 2013; Gilbert, 2009; Mazoue, 2012; Ram, 2011; Rule & Modipa, 2011; Singh, 2010). There is also research on people with „hidden“ disabilities both within and outside of the education arena (Davis, 2005; Fitzgerald & Paterson, 1995; Royster & Marshall, 2008; Valeras, 2010), but very little research has combined all of these factors as one area of focus, or within a South African context. There is a lacuna in the South African scholarship on these issues. While a number of postgraduate studies undertaken at the University of KwaZulu-Natal have focused on learning and disability, including intellectual disability (Francis, 2013; Gilbert, 2009; Singh, 2010), physical and visual disabilities (Chappell, 2013), and deafness (Mazoue, 2012; Ram, 2011), none have examined chronic illness as a „hidden“ disability among adult learners in higher education. The above literature is examined in more detail in chapter two.

On a personal note, part of my rationale concerns my own experience. After years of „mysterious“ illness and many doctors“ visits, I was finally diagnosed in 2009 with systemic lupus erythematosus (SLE), a serious, chronic, autoimmune illness. Living with chronic illness, whilst trying to further my education, has been incredibly difficult. I often felt alone, disbelieved, misunderstood, disheartened and frustrated. The „hidden“ nature of my illness made it difficult for those in my life to understand what I was going through. On the surface I looked well and, because I looked well, I was expected to perform at a certain level. When I could not perform at that level I was a failure in their eyes. This impacted on me in immeasurable ways and, even though today those in my life have a better understanding of my illness, the psychological impact of the accusations and disbelief has made its mark. Not only has the physical toll of my illness affected my learning, but the psychological aspects of living with this illness have shaped my learning experience and how I access help.

This research study includes my own story, and so I play the roles, in complex relation, of both researcher and participant. In addition, I wanted to provide the space for other chronically ill students to share their own stories and in turn provide insight into the challenges and experiences they face in higher education. Fuller, Bradley and Healy (2004) state that “[d]espite a growth of interest in widening access and participation and in inclusive higher education, the voices of disabled students themselves have hardly been heard” (p. 455). By exploring these students“ storied lives, one can gain a better understanding of the functioning and needs of this under-researched group. This may have important implications for how universities will reach and accommodate these students in the future.

1.4 Problem Statement and Research Question

Chronic illness can potentially limit the performance of adult learners in study-related functions such as concentrating, reading, writing and conversing, as well as restricting their participation in learning situations (Jung, 2002; Olney & Brockelman, 2003; Sierra-Zarella, 2005; Valeras, 2010; Vavouraki et al., 2009). The issues associated with living and studying when chronically ill are convoluted by a myriad of interlinking psychological, cultural, social and historical aspects.

Chronic illness is often unapparent to observers. Due to its hidden nature, those who are chronically ill are afforded a choice, albeit often not an easy one, whether to disclose their

illness or not. The hidden nature of chronic illness and its impact on disclosure or non-disclosure (Charmaz, 2002) is further complicated by a variety of interlinking factors such as issues of identity (Charmaz, 1983; Fitzgerald & Paterson, 1995; Shakespeare, 1996; Valeras, 2010), help-seeking behaviour (Olney & Brockelman, 2003; Trammell, Hathaway & College, 2007), perception management (Charmaz, 2002; Olney & Brockelman, 2003; Sierra-Zarella, 2005; Valeras, 2010), coping skills (Giancola, Grawitch & Borchert, 2009) and social stigmatisation (Charmaz, 2002; Davis, 2005; Hammer et al., 2009; Kehoe, 2009; Olney & Brockelman, 2003; Sierra-Zarella, 2005; Wendall, 2001). These aspects influence a chronically ill student's management and subsequent success or non-success in a higher education context. Thus, the issue of disclosure has an important bearing on understanding the challenges and experiences faced by chronically ill adult learners in higher education.

This study concentrates on chronic autoimmune and fatigue-related illnesses and will be termed as „hidden“ disabilities. The label „hidden“ disability has been used in literature to describe a number of disabilities such as cognitive, emotional and learning disabilities (Chalkley & Waterfield, 2001; Olney & Brockelman, 2003; Wolf, 2001) and other chronic conditions such as epilepsy and asthma. For the purposes of this study, „hidden“ disabilities are understood as autoimmune illnesses like systemic lupus erythematosus and biomedically invisible diseases such as fibromyalgia and chronic fatigue syndrome (Davidson & Diamond, 2001; Davis, 2005; Japp & Japp, 2005; Lahita & Yalof, 2005; Macintyre, 1992; Page, du Toit, & Page, n.d.). The term „hidden“ is used in this study, not only because chronic illness often lacks external identifying features, as indicated above, but also because due to this „hiddenness“, those who are chronically ill have a choice whether to hide or disclose their condition to others. This, consequently, has implications. These implications are examined in the subsequent chapters of this dissertation.

The main research question in this study is: **“What are the experiences and challenges faced by adult learners with ‘hidden’ disabilities in the higher education context?”**

Stemming from this main research question, three sub-questions were formulated.

1. How does living with a chronic illness impact on these students' ability to learn and succeed in their education?
2. What coping techniques do these students use to manage their learning experiences?

3. How do these students understand and project their identities?

1.5 The Aim of this Study

The purpose of this study is to gain insight into the lives of chronically ill adult students as they navigate their way through higher education.

The specific objectives are to explore the experiences and challenges of chronically ill adult students in higher education

- to understand the impact of their illnesses on their learning and their day to day lives
- to identify and elaborate the techniques that these students use to manage and cope with their learning
- to investigate the ways in which these students understand and project their identities

1.6 Important Definitions and Conceptual Terms

Adult Learner

Defining the adult learner is not as simple as it would seem. What it means to be an adult and who is labelled as such, is a complex and broad debate that is beyond the scope of this dissertation (Buchler et al., 2004). The current legislation in South Africa defines a „mature age“ learner as someone who is 23 years or older but, as Buchler, Castle, Osman and Walters (2004) note, defining an adult learner by the characteristic of age is narrow and problematic. I would like to include additional characteristics, noted by Bourgeois, Duke, Guyot and Merrill (1999, cited in Buchler et al., 2004), of a person who has had a substantial gap, due to other adult commitments and responsibilities, before entering or re-entering higher education. As I am particularly interested in the more mature adult learner, this definition is more encompassing and provides for the richness and complexities of the roles and life experiences that this type of student brings to the learning experience. I recognise that the terms „adult learner“ and „mature adult learner“ can be construed as two categories of adult learners, one of which is merely defined by age and the other a more complex definition including life experience and maturity, but for the purposes of this dissertation I use the term adult learner and mature adult learner interchangeably on the understanding that my definition of both

favours the more mature, experienced adult learner as my subject, as described above by Bourgeois, Duke, Guyot and Merrill (1999, cited in Buchler et al., 2004).

Illness versus Disease

A distinction needs to be drawn between disease and illness. Although the definition of chronic illness below refers to disease, it is illness or the subjective experience of living with an illness and its effects that I am particularly interested in (Helman, 1981). This study does not profess to be a medical study, but rather a narrative exploration of the lived experiences of adult students who are chronically ill. The term „disease“ has medical/epidemiological connotations where bodily symptoms and causes are the focus, whereas „illness“ includes the person’s experience of the condition.

Chronic Illness

Chronic disease has been defined as illness that is prolonged in duration, does not often resolve spontaneously, and is rarely cured completely. Chronic diseases are complex and varied in terms of their nature, how they are caused and the extent of their impact on the community. While some chronic diseases make large contributions to premature death, others contribute more to disability. (Australian Institute of Health and Welfare, 2012, p.5)

Autoimmune Illnesses

There is an enormous variety of chronic illnesses and it would be impractical to include them all within the scope of this study; therefore I decided to narrow the scope of this study to people with autoimmune illnesses.

Autoimmune diseases refer to problems with the acquired immune system’s reactions. In an autoimmune reaction, antibodies and immune cells target the body’s own healthy tissues by mistake, signalling the body to attack them... Autoimmune diseases can affect almost any part of the body, including the heart, brain, nerves, muscles, skin, eyes, joints, lungs, kidneys, glands, the digestive tract, and blood vessels. (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2012, p.1)

Participants who have autoimmune illnesses such as lupus, early stage multiple sclerosis and rheumatoid arthritis, as well as those who are afflicted by so-called „mystery“ illnesses such as chronic fatigue syndrome and fibromyalgia, are the focus of this study (Lahita & Yalof, 2005; Macintyre, 1992). The symptomologies of these illnesses are similar in nature and therefore I grouped them together even though their causes, diagnostic criteria and treatment can differ. Importantly, these illnesses are not immediately apparent to a casual observer and have similar characteristics such as inflammation, nausea, fatigue, pain and general feelings of malaise (Davidson & Diamond, 2001; Lahita & Yalof, 2005; Macintyre, 1992; Page et al., n.d.)

1.7 Theoretical Frameworks

In order to conceptualise and provide a way of understanding the experiences and challenges of adult learners with „hidden“ disabilities within an educational context, a single theoretical framework is insufficient. As was hinted at previously, and is discussed in more depth in chapter two, there are multiple interacting factors that will influence the lifeworld of a chronically ill adult learner. Thus, I chose a number of theories and models for the purposes of this study with the goal of providing an integrated approach that draws from different disciplines in order to best provide a more comprehensive, integrated theoretical framework.

A Disability Model

As we delve deeper into the literature concerning disability and chronic illness in the following chapter, it becomes clear that traditional models of disability (medical model and social model) cannot sufficiently explain the multifaceted and complex nature of disability. In particular, the traditional models do not provide a complete framework in and of themselves in which chronic illness can be understood. Thus, the interactional model (Rule & Modipa, 2011; Shakespeare, 2006; Shakespeare & Watson, 2001) appears to be broad enough for the purposes of my study, which encompasses biological, cultural, psychological and social aspects that create and/or compound disability. The interactional model's universal approach has the potential to embody and represent the lived experiences of persons with disabilities.

This model provides a framework that assists in the conceptualisation and data analysis of the study at hand, and although comprehensive in many ways due to the complex identity formation aspect and context-dependent shifting of identities in this study, an additional framework that is specifically focused upon identity construction is required.

An Identity Theory

The Dialogical Self Theory postulates that we have many selves, or I-positions, which vary depending on context and/or the different people we interact with; thus, the Dialogical Self Theory provides a relevant framework for this research (Hermans, 2001; Hermans & Hermans-Konopka, 2010a). Multiple selves are created through the continuous, dynamic dialogue between a person's many I-positions and the external other, where roles and positionings are negotiated and renegotiated in an ever-changing social context. An individual's multiple selves exist on an internal and external level and evolve and change as they interact and dialogue with each other, thus creating new I-positions and roles (Hermans, 2001; Hermans & Hermans-Konopka, 2010a). A more in-depth discussion of the Dialogical Self Theory follows in chapter two, which illustrates the nature and construction of these multiple selves and positions within and as part of the greater cultural and social context. In short, the Dialogical Self Theory conceptualises the self as multiple, developing, changeable and dynamic in nature. This theory provides a framework in which the shifting identities of people with „hidden“ disabilities can be understood and through which related data can be interpreted in a meaningful way.

A Learning Model

As this study is set within an educational context, it is fitting to include a theoretical framework that concerns learning. Jarvis proposes a holistic learning theory which is in keeping with the underlying assumptions, methods and aims of this study. Jarvis (2009) believes that learning is intimately tied with humanness. Learning and being human are inextricably linked and thus, in order to study and understand learning, one must first understand and consider the person holistically. Learning, according to Jarvis (2009), involves the entire person, both body and mind, within a social context. This understanding of learning has particular import when considering the impact an ill body, tired mind and less than supportive social context could have on one's ability to learn. Jarvis (2009) goes on to

explain that learning occurs when there is a state of disjuncture or a state of unknowing. Disjuncture is a catalyst for learning, as it requires a person to make a choice to either accept this state of unknowing or move forward by acquiring and assimilating knowledge to bridge this proverbial gap. This process engenders personal transformation which, in theory, begins to transform the learner's social context. Disjuncture, the process and tools of learning and the resultant personal transformation are explored in the following chapter.

1.8 Research Design and Methodology

Research Paradigm

Due to the typical nature of disability research, which often focuses on power relations and societal structuring, a critical paradigm is frequently adopted, but for the purposes of this study, I chose an interpretive paradigm. The exploratory nature of this study required a paradigm that embraces and positions at the forefront the perceptions and worldviews of those whom we wish to understand. The interpretive paradigm is based on the premise that understanding is achieved through gaining insight into how a person constructs and creates meaning within their world (Lewis-Beck, Bryman & Liao, 2004; Nudzor, 2009; Terre Blanche & Durrheim, 2006). These perceptual understandings can be conveyed through storytelling and thus afford us a glimpse into the lifeworld of adult learners with „hidden“ disabilities. Narrative inquiry, a fitting methodology that can be neatly underpinned by the interpretive paradigm, allows for storytelling that privileges the narrator's voice. In short, the paradigm and methodologies I chose, which are discussed in greater detail in chapter three, worked together to provide an optimal platform that elicited genuine reflections of life as it is lived in the context of „hidden“ disabilities.

Style

I chose a qualitative stance due to the focus on narrative and the interpretive nature of this study. Creswell (2009) explains that “[q]ualitative research is a means for exploring and understanding the meaning individuals or groups ascribe to a societal or human problem” (p. 4). The purpose of this study is to gain insight into the lives of chronically ill adult students as they navigate their way through higher education. Thus, a qualitative approach, which primarily focuses on providing an in-depth understanding of the lived experiences of people,

fits with the study's aims. Qualitative research is based on the premise that people actively construct their own realities through meaning making, therefore research methods that can uncover these processes are critical to research of this nature (Boeije, 2010).

Approach and Methods

Narrative inquiry is a qualitative research approach that privileges the subjective, inner worlds of people. It is a fitting approach for understanding the challenges and experiences faced in higher education by adult learners with „hidden“ disabilities. It affords a platform for storytelling that can illuminate and provide understanding of their subjective experiences and their process of meaning making (Sikes & Gale, 2006). Connelly and Clandinin (1990) add that “[t]he main claim for the use of narrative in educational research is that humans are story-telling organisms who, individually and socially, lead storied lives. The study of narrative, therefore, is the study of the ways humans experience the world” (p. 2). I chose narrative interviewing for the data collection as it fits with the nature and aims of the study. Narrative interviewing allows for authentic storytelling which can potentially reveal the perceptions, inner thoughts and experiences of those who are being interviewed. I adopted thematic analysis in order to code and organise the raw data elicited from the interviews into significant themes and patterns. I analysed these themes and patterns in conjunction with the theoretical frameworks identified earlier in order to provide insight into the challenges and experiences faced by adult learners in higher education with „hidden“ disabilities (Braun & Clarke, 2006; Guest, MacQueen & Namey, 2012; Merriam, 2009; Suter, 2012). An extensive discussion of thematic analysis follows in chapter three.

Sampling

Studying hidden populations has a number of barriers, one of which is identifying members of the population concerned. Snowball sampling has been recognised as advantageous in studying these types of populations (Atkinson & Flint, 2001). A discussion follows in chapter three on how snowball sampling works in this environment, and its advantages and disadvantages are explored.

For the purposes of this study, I used a snowball sampling technique to select four chronically ill adult learners at various South African tertiary institutions with autoimmune or chronic

illnesses with comparable symptomology. In this sample, I also included myself as a participant, making a total of five participants. They were selected on the basis of the following criteria:

- registered students at a South African university or higher education institution
- mature adult student (as defined above)
- autoimmune illness or chronic illness with similar underlying symptomology such as fatigue and pain – the condition may either be diagnosed or undiagnosed

The participants of this study were middle class, English-speaking, women ranging in age from early thirties to mid-fifties, from various cultural and ethnic backgrounds. At the time of data collection, all of them were involved in studying (from undergraduate to postgraduate) with the exception of one, who had just submitted her thesis. Disciplines ranged from law and education to theology.

Trustworthiness

The qualitative equivalent to validity and reliability is trustworthiness. Certain aspects must be incorporated into the research in order to ensure its trustworthiness. These aspects are transferability, credibility, dependability and confirmability (Merriam, 2009; Rule & John, 2011). In an effort to maintain trustworthiness, I included elements within this study in order to meet the criteria needed to fulfil each of the various elements of trustworthiness. These elements of trustworthiness, transferability, credibility, dependability and confirmability are discussed in detail in relation to the study in chapter three.

1.9 Ethics

Given the „hiddenness“ of the kinds of disabilities on which this research focuses, and the potential vulnerability of participants, applying appropriate research ethics was of particular importance. Ethics plays a role in the validity and reliability of the research (Merriam, 2009). Three important aspects that need to be taken into consideration are autonomy, non-maleficence and beneficence (Rule & John, 2011). These students shared their personal stories about living with a „hidden“ disability. They and their stories needed to be treated with

respect, dignity and value; therefore each of the participants was informed of the exact nature and purpose of the study, how long they would be required to participate and the exact nature of their participation. They were informed that they had the opportunity to withdraw from the study at any time. Counselling services were also made available to the participants.

All efforts were made to ensure that the participants' privacy, anonymity and confidentiality were maintained and protected.

1.10 Preview of Chapters

The next five chapters deal with the following:

Chapter 2: Literature Review

This chapter reviews the relevant literature in order to understand the complex range of experiences and challenges faced by mature adult learners in higher education with „hidden“ disabilities. Furthermore, it incorporates the applicable theoretical frameworks, which were used to gain insights into the narratives shared by the participants, in correlation with the related research. Numerous areas of research were analysed and included in the literature review due to the multifaceted nature of the research question. The chapter discusses Adult Education and Disability; Chronic Illness as a „hidden“ disability; Disability, Identity and Social Context; and lastly, Disclosure and Non-Disclosure in connection with the research question and the relevant theoretical frameworks.

Chapter 3: Research Design and Methodology

An analysis of the research methodology and its applicability to the research at hand is detailed in this chapter. The qualitative style and narrative approach, underpinned by the interpretive paradigm, are discussed in terms of their relevance to the study. Additionally, the chapter provides a comprehensive discussion on narrative interviewing and thematic analysis as the methods adopted for the data collection and data analysis respectively in this study.

Chapter 4: Narratives

Drawn from the in-depth interviews, the narratives shared by the participants are presented in this chapter in order to provide a deeper understanding of the participants storied lives. These narratives are structured in terms of identity and background; diagnosis and experiences of illness; studies and experiences of learning and work-family-study commitments; coping and support networks; and learning about themselves. These narratives provide a basis for understanding the individuals' experiences and challenges of living and studying with a „hidden“ disability.

Chapter 5: Analysis and Discussion

This chapter details and examines the predominant themes and patterns, which emerged from the narrative interviews, through the use of thematic analysis. These themes are discussed, using the theoretical frameworks as lenses in order to analyse and provide illumination of the data.

Chapter 6: Conclusion

This concluding chapter amalgamates the discussions and findings that emerged from this study. The findings and the relevant literature are discussed in light of the initial research questions. Leading from this, the implications and recommendations based on the study's findings, and a synopsis of the study's limitations, are discussed. This chapter also shares and reflects upon the research process itself and researcher insights. Finally, it concludes with a review of future research possibilities.

1.11 Conclusion

There is a need for further research in the field of adult education and disability, and in particular, adult learners with „hidden“ disabilities in the higher education environment. Chronic illness, and specifically autoimmune illnesses, has far-reaching implications for those affected by them. For persons with a chronic illness, who have endeavored to further their tertiary studies, the combined difficulties of dealing with ill health which is not necessarily apparent to others, in conjunction with the stressors and strains of adult

responsibilities, can negatively impact on their learning success. International and national organisations and governments have earmarked, as a fundamental concern, accessibility to education and appropriate accommodation for people with disabilities. The South African Department of Education has highlighted that there is scant research on disability in education and more is needed in order to understand and meet the needs of people with disabilities – a call to which this study attempts to respond.

The purpose of this study is to provide awareness and understanding of chronically ill adult students' lifeworlds in higher education. This under-researched „hidden“ population of students warrants further study in order to better understand their experiences and challenges; this could potentially provide insight into how higher education institutions can assist them.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The literature review plays an important role in situating the research problem within the context of related research. It provides important information on what has been researched, the theories that are crucial to the research in question and the gaps or areas that have previously been neglected. A literature review is a synthesised, critical evaluation of previous research, which provides a foundation for one's own study and situates it within the „bigger puzzle“. It helps one identify important links and relationships between variables and appropriate methodologies. Essentially, it determines if the research question or problem warrants further investigation and provides a rationale or justification for the investigation. The literature review helps one establish what theories are important to understanding the research problem and, in turn, can suggest a theoretical framework in order to conceptualise and analyse the information garnered from one's study (Boote & Beile, 2005; Oliver, 2012).

In order to understand the complexities of the experiences and challenges faced by mature adult learners with „hidden“ disabilities in higher education, multiple areas of research needed to be analysed and included in the literature review. A more in-depth discussion follows.

Chronic illness is variable, fluctuating and unpredictable, ranging from mild to extremely debilitating conditions which impact on a person's health and subsequent quality of life (Laidmäe, 2012; Wendell, 2001). Chronic illness can develop at any point in a person's life; it does not discriminate on the basis of race, age or gender. Chronic illness is often epitomised by fatigue, pain, dizziness, inflammation and nausea (Jung, 2002; Wendall, 2001) which contribute to “limitation[s] in mobility and inability to perform the activities of daily living” (Jung, 2002, p. 180). These limitations carry through into the educational context. A mature adult learner in higher education, who already has to contend with certain barriers and challenges, may incur additional stressors and difficulties, if chronically ill. This may significantly impact upon the success of their learning experience, as it can potentially limit functioning in study-related tasks, as well as involvement in and contributions to learning situations (Hammer et al., 2009; Jung, 2002; Olney & Brockelman, 2003; Royster & Marshall, 2008; Sierra-Zarella, 2005; Vavouraki et al., 2009). Understanding the experiences and challenges faced by these learners requires an exploration of a number of important

themes. These themes include the following: adult education and disability; chronic illness as a „hidden“ disability; disability, identity and social context; and lastly, disclosure and non-disclosure. Within these themes I also explore and incorporate the relevant theoretical frameworks that provide explanation, context and background to the issues at hand.

2.2 Adult Education and Disability

The research topic of adult learners with disabilities has largely been overlooked within adult education (Clark, 2006). In order to understand the disability experience and its impact within the adult education arena, further research is required (Clark, 2006). In South Africa, there is insufficient “knowledge of the educational attitudes and experiences of adult learners with disabilities” (Rule & Modipa, 2011, p. 3).

An interdisciplinary approach between disability studies and adult education can play an important role in helping to understand the experiences and functioning of adult learners with „hidden“ disabilities. One of the goals of adult education is to raise “consciousness about social justice and oppression toward communities of people whose voices are often silenced because of the marginality of difference” (Clark, 2006, p. 315). The voices of chronically ill adult learners have largely remained unheard; therefore, further research to gain insight and understanding of this type of disabled adult learner is sorely needed.

A theoretical framework that can explain the disability experience and how it impacts on the learning experience, within adult education, is yet to be developed (Clark, 2006). It is essential, in order to facilitate equal access and participation for disabled adult learners within the learning arena, that a working theoretical framework incorporates both a disability and an adult education focus. An interdisciplinary approach can provide a lens to examine and better understand the issues that contribute towards barriers and other relevant push and pull factors experienced by learners with disabilities. The interplay between disability, psychological process, identity formation and sociocultural issues has important implications for the study of adult education and the learning experience. Clark (2006) adds that the “disability identity and its social processes can provide researchers of adult education new ways of thinking and understanding the notion of identity theories within the learning context” (p. 317). Clark provides several examples of gaps within adult education research which would benefit from an interdisciplinary approach. She explains that some previous adult education research has

failed to recognise that the learning needs and the required accommodations vary for different disabilities and that a „one-size-fits-all“ mentality is flawed. She also explains that previous research has given little attention to the “complex social and lived realities that adult learners with disabilities face outside of the learning context” (p. 312). She further notes that adult education theories that focus on barriers to learning have not fully integrated and analysed the disability experience and its impact on the learning experience (Clark, 2006).

Writing within a South African context, Howell (2006) explains that the barriers and psychosocial stressors experienced by students with disabilities within the higher education context can have a detrimental effect on their academic success. Barriers arise from a number of sources ranging from inequitable access to and participation in higher education, the functional and structural aspects of the institution, lack of resources to accommodate disabled students, dominant discourses that inform and guide educational policies and issues inherent within the learning and teaching process, assessment practices, classroom management and even the curriculum itself. Ineffective, inclusive learning and teaching practices within higher education institutions and minimal flexibility in the curriculum play a primary role in creating barriers to participation. Additionally, barriers to curriculum access have been brought about through the way learning support services for disabled students have been construed and implemented, for example, the notion that assisting the student with a technological device within the classroom will ultimately solve the „problem“. This thinking is flawed, as it does not consider the social context of disability and therefore fails to initiate the change required for an effective learning environment that ensures equality. Furthermore, most institutions that do provide learning support services for disabled students do so in isolation from the typical learning and teaching practice and support systems in place. Generally, support services for disabled students work in conjunction with student counselling services instead of in collaboration with academic development services (Howell, 2006).

Howell (2006) argues that disabled students, who are not provided with the accommodation required for equitable access and participation in educational institutions, can suffer significant psychosocial stressors, which may result in failure and drop-out. On the other hand, students who do succeed may do so by engaging in “self-injurious behaviour” (Howell, 2006, p. 175). These students over-compensate and push themselves, often beyond their limits, such as by working extremely long hours in order to „keep up“ with other students. The ongoing pressure to overcome these types of barriers places these students at a

continuous disadvantage to other students. This pressure results in high levels of stress and an additional strain on the student's energy and emotional reserves. This disadvantage forces these students to perform at a level not required from other students and, when they cannot perform at this level, the negative attitudes from staff and other students towards them are „confirmed“.

These prejudices and attitudes can result in the continued complacency of an institution that typically falls back on dominant medical discourses, which situate the problem within the individual, with little need for accountability and change.

The above mentioned barriers and psychosocial stressors associated with being disabled can be presumed similar for a mature adult learner in the same educational context with the exception that they would face additional challenges and difficulties unique to being a mature adult student in higher education (Buchler et al., 2004; O'Donnell & Tobbell, 2007). It would be prudent to add that although mature adult learners face particular barriers, they also have advantages that they bring to the higher education context. Their maturity, vast reservoir of experience, self-knowledge, motivation and self-management, amongst other positive traits, assist them in learning (Howell, 2004; McGivney, 2004; Richardson & King, 1998). The above mentioned barriers and stressors, as well as the unique advantages that the adult learner brings to the higher education learning context, are analysed in more detail later.

2.2.1 Jarvis' Holistic Learning Theory

As this dissertation explores the experiences of chronically ill adult learners in higher education, it would be prudent to include a learning theory that can provide a theoretical framework for this learning context. Jarvis' holistic approach to learning fits the overall tone, intent and focus of the research project at hand.

According to Jarvis (2009), learning is essentially human or an expression of being human, and in order to study learning, it is imperative that one understands the person or learner in their entirety. Jarvis (2009) believes that learning is an existential phenomenon that concerns the whole person, body and mind as they interact with and experience their world throughout their lives. Jarvis understands and terms human beings as existents and our minds and/or self as our essence (Jarvis, 2005). He explains the learning process as “that of the human essence

transformed into skills, attitudes and knowledge, into a definition that highlighted learning as a process that involves the whole person within a social situation.

Human learning is the combination of processes throughout a lifetime whereby the whole person – body (genetic, physical and biological) and mind (knowledge, skills, attitudes, values, emotions, beliefs and senses) – experiences social situations, the perceived content of which is then transformed cognitively, emotively, or practically (or through any combination) and integrated into the individual person’s biography resulting in a continually changing (or more experienced) person. (Jarvis, p. 25, 2009)

Learning, as both an existential and experiential process, is a dynamic phenomenon that begins, as it has been argued by a number of academic disciplines, before birth in the womb and continues until we die (Jarvis, 2009). Crucial to Jarvis’s model of learning, is that learning is social and that mind and body are integral parts of that process. Jarvis contends that we experience the world through our bodies. The bodily sensations that we experience as we interact with our world are the origins of our learning. As we feel, touch, taste, see and smell the world around us, we, through cognitive processes, give meaning to these sensations. This first-stage learning does not occur in isolation, but rather it is socially constructed, therefore “nearly all meanings will reflect the society into which we are born” (Jarvis, 2009, p. 25). Jarvis goes on to explain that, as adults, we tend to take for granted many of our experiences as being similar and categorise and organise them as such, even though in reality our world is in constant flux. This categorisation process is of course essential in order for us to make sense of the world and provide some kind of structure to our life-world.

Children tend to experience disjuncture more frequently than adults, as many of the sensations they experience are novel and without meaning, but this is not to say that adults do not experience disjuncture of this nature too. Adults, from time to time, do encounter sensations that are unfamiliar to them, which create disjuncture or a sense of not-knowing, which in turn raises questions and an opportunity for learning. The adult provides the sensation with meaning: “It is in learning the meaning, etc. of the sensation that we incorporate the culture of our life-world into ourselves; this we do in most, if not all, of our learning experiences” (Jarvis, 2009, p. 26). These primary learning experiences occur for both adults and children and continue throughout the life span. Jarvis (2009, p. 26) details this process in the diagram below.

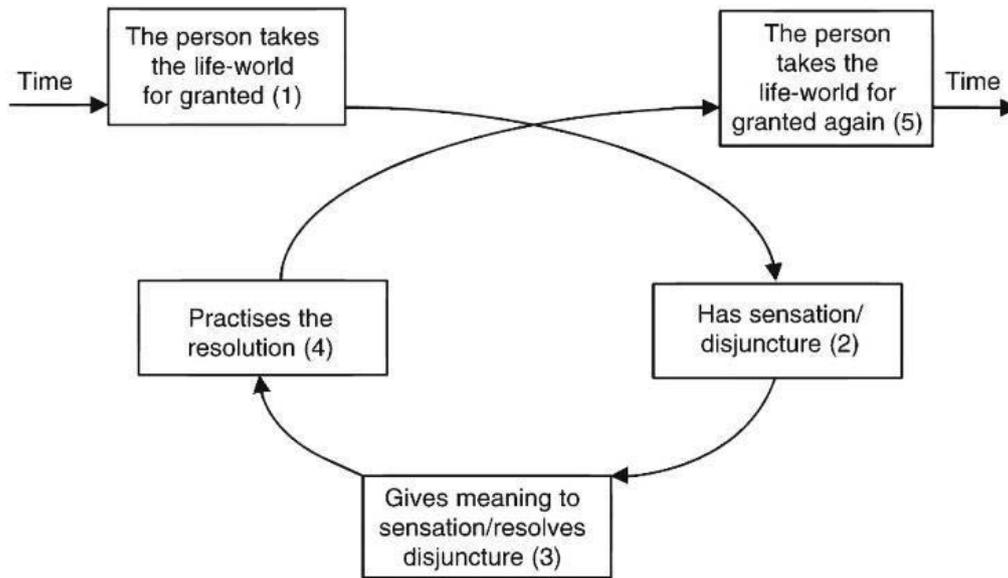


Figure 2.2: *The Transformation of Sensation: Learning from Primary Experiences*

Once the disjuncture has occurred, it is resolved by applying a socially acceptable „answer“ or meaning to it; but it should be noted here that, although we tend to strive for conformity and validation from society that our „answer“ or meaning is indeed „correct“, we can also learn to disagree with society and through this process establish our individuality (Jarvis, 2009).

Once the „answer“ or meaning has been found, it is then practiced, repeated and committed to memory and the person, more often than not, reverts back to taking the world for granted. Through this process, however, we do change, as do others, and in turn, our social world changes, “so our taken-for-grantedness becomes more suspect (Box 5) since we always experience slightly different situations” (Jarvis, 2009, p. 27). This primary learning assumes a pattern whereby future experiences of sensations tend to be less significant by default as the socially acceptable meaning previously assigned to the sensation dominates and therefore takes precedence throughout the process.

Although sensations still occur throughout the life span, people just become less aware of them. Therefore, future disjuncture generally occurs around meanings rather than sensations. Sensations are relegated into the background and cultural meanings come to the fore as we

become more concerned with meanings or words that we do not know. These secondary experiences are mediated through speech, written word and so on. Jarvis (2009) highlights that in this secondary process, “cognition becomes central to learning and while we still have the primary experience, it is relegated to a subsidiary position in the hierarchy of human learning” (p .28). Jarvis (2009, p. 29) details this secondary process in the diagram below.

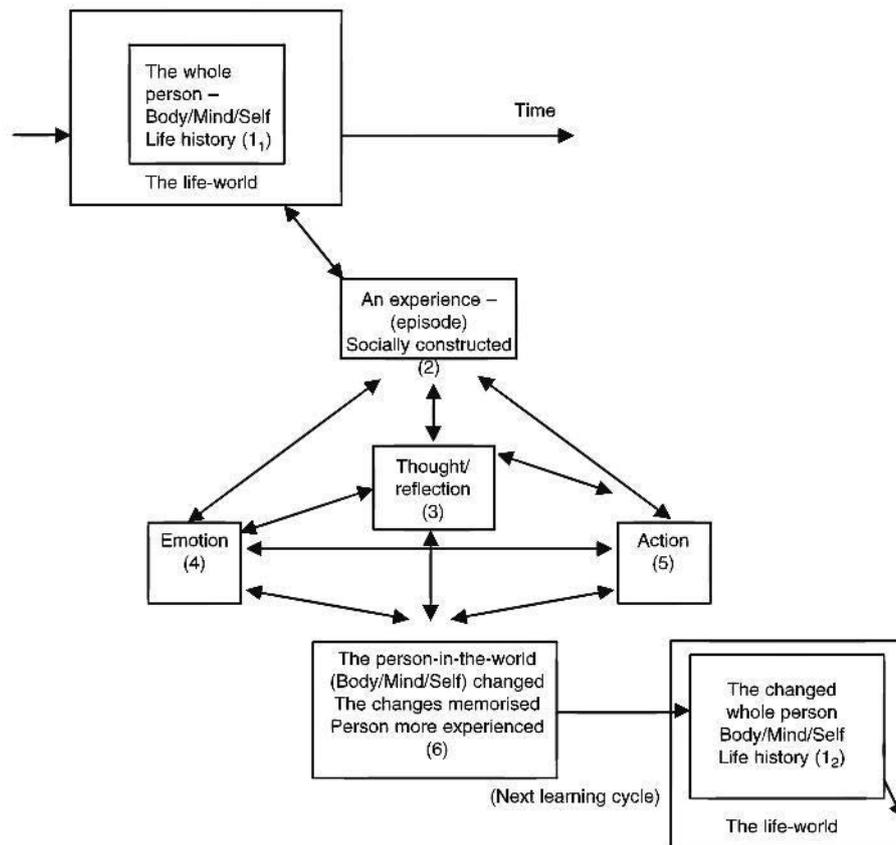


Figure 2.3: *The Transformation of the Person through Learning*

Ultimately, Jarvis contends that a person is transformed through learning. As depicted in the above diagram, the whole person (body/mind/self) in their life-world experiences disjuncture. Following that experience, the person responds in a number of ways (boxes 3-5). These responses do not occur in isolation, but rather there is a dynamic interaction between them as at each point of learning (response or action) there is an opportunity for feedback and possible redirection. Here, Jarvis purports, we learn from the experience itself, not the social context it is found in, nor from the sensation and its assigned meaning. Through learning, people change and ultimately so too does the social situation in which their interactions occur. A person and their life-world are transformed through learning. Essentially, learning is

a series of transformations, namely, a transformation of sensation, the person and the social context. Learning involves the simultaneous and complex processing of primary and secondary experiences, where sensations and meanings provide the basis for learning (Jarvis, 2009).

2.2.1.1. The Learning Process

An individual learns within a social context and, through this process, internalises his or her life-world's culture.

The culture is internalised and carried by individuals so that when people meet, the commonality of their cultures enables meaningful meeting to occur. In social interaction there is always an exchange of sub-cultural differences and individuals adjust in response to those differences – in other words learning takes place. (Jarvis, 2012, p. 5)

This type of learning is incidental in nature and often passes unnoticed. The same can be said of sensations or sense experiences for adults, as their focus is primarily on the cognitive dimension, and as the disjunctures surrounding most sensations have been resolved and therefore become taken for granted. Children, however, tend to be more aware of sensations, as they are still grappling with these primary learning experiences. This initial learning tends to be non-reflective. Once an individual moves into the cognitive realm, disjuncture occurs around meanings or “not knowing the meaning of the event or of some aspect of the experience” (Jarvis, 2012, p. 7). This type of disjuncture can be created in a formal setting such as in the classroom, but it also occurs naturally in everyday life as we interact with each other and our world. These secondary experiences are transformed through thought, action and/or emotion and the outcome of such is either a resolution of the disjuncture, or a failure to do so. Jarvis (2012) points out that, even if the disjuncture is not resolved (and this can happen), the process always results in changing the person; even if it seems that no learning has taken place. Jarvis (2012) emphasises that it is important to understand that the human process of learning stems from the complex interaction between the person as an individual and the context within which the experience takes place, which creates different learning experiences.

[T]here is no difference in the human process in different forms of learning, so that we do not have formal learning, non-formal learning and informal learning but we do have formal interaction, and so on. It is the nature of the interaction that provides for different learning experiences and it is these that affect emotion, motive to learn, and so on. (Jarvis, 2012, p. 10)

2.2.1.2 Conditions of Learning

As previously discussed, learning requires social interaction. As social beings we interact with each other and through this interaction we are confronted with our differences and in turn this creates disjuncture. Jarvis (2012) explains that “[s]ocial interaction involves exploring difference and adjusting our behaviour to enable the interaction to proceed smoothly” (p. 11), thus through this process of adjustment and accommodation, we learn. Alternatively, one can demonstrate non-learning whereby a person refuses to change their behaviour or adapt. This can be seen as a strength, particularly in the face of social pressure to conform, but can just as well translate into intolerance and inflexibility (Jarvis, 2012).

Disjuncture and subsequent learning occurs when we become aware that we are in a position of unknowing (Jarvis, 2012). We have different responses to disjuncture, whereby we can decide to make peace with the fact that we will always be ignorant in a particular area of knowledge or take steps to learn and assimilate that knowledge in order to close the gap between us and our world and once more be in harmony. The resultant disjuncture that occurs from a small gap in knowledge can be remedied by minor adjustments which often go by unnoticed as they fade into the background of everyday living and passage of time. Alternatively, disjuncture can occur on a major scale, requiring intensive studying and training in order to close the gap: “There is a sense in which learning occurs whenever harmony between us and our world has been broken, so that the relationship between our present understanding and our experience of the „now“ needs to be established, or re-established” (Jarvis, 2012, p.12).

2.2.1.3 Jarvis' Learning Theory and Chronic Illness

Jarvis' theory's special focus on sensation and body, as an integral and primary aspect of learning, has interesting repercussions when considering the experiences and sensations that a body which is ill may have in comparison to someone who is well.

By adulthood, most sensations have lost their novelty. These sensations have been assigned socially acceptable meanings and mostly exist below normal levels of awareness, but with the onset of chronic illness it can be assumed that a range of new sensations and primary learning experiences will come to the forefront as the adult grapples with and tries to assign meaning to bodily sensations characterised by pain, fatigue, general malaise and fluctuating symptomology. Primarily, chronic illness creates disjuncture. Resultant learning or even „non-learning“ created by this disjuncture can occur. Disjuncture creates opportunity for learning: “we have to find new explanations, new knowledge, new ways of doing things” (Jarvis, 2012, p. 2). Herein lies the conundrum; someone who is chronically ill is dealing with and processing a multitude of primary experiences. This begs the question, how does this impact on learning in a formal context or secondary learning experience when so much energy and time is devoted to dealing with and learning to live with chronic illness? It is also important to consider that, although disjuncture creates opportunity for learning, it can also result in „non-learning“. This „non-learning“ may present itself as a refusal to learn new ways of „being“ and „doing“ or even as a denial of the chronic illness and its resultant impact. It can be construed that this „non-learning“ in someone who is chronically ill could have serious ramifications on secondary learning experiences, as their ability to function, adapt and make space for a new way of living is compromised.

2.2.2 Adult Learners in Higher Education

Within the South African context, research conducted into adult learners, as defined in chapter one, in higher education is sparse (Buchler et al., 2004). A review in 2004, of research on adult learners within South African higher education explains the following:

There is little information, at the systems level, on „deeper“ questions, such as the push/pull factors for adult learners entering higher education, the barriers they face

and experience once in higher education institutions, their success and completion rates, and their reasons for entering HE institutions. (Buchler et al., 2004, p. 124)

Due to the transformation of the world economy, there is a greater demand for a highly educated work force, thus more adults are returning to higher education to better their education and, in turn, to improve their earning potential and job prospects (Buchler et al., 2004; Kazis et al., 2007). This influx of „non-traditional“ learners has changed the demographic of the „higher education student“ which has brought about a new set of challenges, not only for the students themselves, but also for higher education institutions (Buchler et al., 2004; Kazis et al., 2007). The adult higher education student is faced with a number of barriers such as working full or part-time, taking care of dependents, financial constraints, access to higher education, lack of support from the institution in question and dealing with a number of other adult responsibilities on a daily basis (Buchler et al., 2004; Kazis et al., 2007; McGivney, 2004; Richardson & King, 1998). Aside from the above mentioned barriers, psychological barriers such as low self-esteem, feelings of guilt for pursuing an education and fears of not being able to cope or fit in, further impact upon an adult learner’s ability to perform academically (Howell, 2004; McGivney, 2004). Due to these barriers, adult learners have lower retention and throughput rates than „traditional“ students (Kazis et al., 2007).

The challenges an adult learner faces are different from the more traditional, 18 to 22 year-old, financially dependent, full-time, higher education student (Kazis et al., 2007), but it is also important to recognise the special skills, resiliency and experience that an adult learner brings to the learning environment. Adults entering into higher education are not empty vessels. They bring to the learning context a wealth of experience, knowledge and life skills, which potentially contribute towards their ability to cope and learn, enhancing their academic performance (Howell, 2004; McGivney, 2004; Richardson & King, 1998).

Although, undoubtedly, adult learners do face barriers to learning they are adept at “more effective and elaborative learning than younger students precisely because they are likely to be far more adept at examining and exploiting their prior experience in order to make sense of new information and new situations” (Richardson & King, 1998, p. 69). Additionally, adult learners seem more adept at time management skills than their younger counterparts and tend to display resiliency, adaptability, resourcefulness, persistence and flexibility crucial

to academic success (Howell, 2004; McGivney, 2004; Richardson & King, 1998). It is probable that these particular traits and characteristics may assist chronically ill adult learners in coping more effectively than a younger chronically ill student in the higher education context.

2.2.3 Adult Learners with Disabilities

Reviewing literature and garnering insight into adult learners with disabilities is pertinent to understanding adult learners with „hidden“ disabilities. It is important to position adult learners with „hidden“ disabilities within the broader spectrum of research on disability and adult learners, in general. Parallels can be drawn between the experiences and challenges faced by an adult learner with „traditional“ disabilities and that of someone with a „hidden“ disability. This is discussed in more detail later. Many of the issues and policies below are relevant to the study at hand due to these parallels.

Not only does an adult learner with a disability have to contend with the barriers of being an adult learner; they also need to grapple with the difficulties and obstacles of having a disability within a learning context, thus making this particular type of student especially vulnerable to academic failure, high dropout rates, exclusion from academic and social opportunities and activities, isolation, discrimination and so on (Clark, 2006; Fuller, Bradley & Healy, 2004; Howell, 2006; Rule & Modipa, 2011). This is in keeping with the concept of intersectionality, whereby overlapping identities compound marginalisation. In this context, being a person with a disability and being an older student may be seen as intersecting oppressions (Collins, 2002, 2012).

Presently, due to the lack of national policy on disability in the post-school domain, higher education institutions are left to deal with disability in a way that they deem fit. Some institutions recognise only certain types of disabilities and vary in the level of assistance they provide (Foundation of Tertiary Institutions of the Northern Metropolis (FOTIM), 2011). A document compiled by the South African Department of Education in 2009, *Support Services for Students with Disabilities at South African Higher Education Institutions* (DoE, 2009), reported on a number of South African universities. The report highlighted services provided by the University of Cape Town, Central University of Technology, Free State, University of Johannesburg, University of Pretoria, Rhodes University, University of South Africa,

Tshwane University of Technology, University of the Western Cape, University of the Witwatersrand, University of Venda and the University of Zululand.

The University of Cape Town's Disability Unit stands out as probably having the most comprehensive disability service in comparison to some of the other universities that appear in this document. Not only do they recognise and make accommodation for the more traditional disabilities, but they also make special mention of chronic illness as a disability and they are supportive of other „invisible“ disabilities such as psychological and learning disabilities. In terms of support, an educational psychologist assesses the student and deems what accommodation can be made such as extra time for examinations or extra tuition in problem subjects, but this does seem to be more geared towards learning disabilities than chronic illness. They also mention the availability of medical and psychological services and that, over and above these services; they will endeavour to address individual needs as far as they can (DoE, 2009).

In general, the University of Cape Town offers, amongst other things, assistive technological devices, particularly for hearing impaired and blind students, physical accessibility to all areas of the university, extra tuition, scribes, help with transportation and accommodation, and flexibility in assessment and teaching methods. They have also endeavoured to actively encourage potential students with disabilities to apply to the university and have put measures in place in order to assist those students in gaining access. They have been actively engaged in community outreach programmes and awareness campaigns, as well as taking steps to provide support to their academic staff in the development of learning and assessment methods to assist students with disabilities (DoE, 2009).

Other surveyed institutions vary in their level of support and what types of disabilities they are able to assist with. Some institutions can only provide very basic support for those with physical disabilities such as disabled parking and certain equipment for the blind and hearing impaired, whilst others provide for a wider range of disabilities. Some universities place special emphasis on society as a source of disability and have programmes in place to create awareness around disability, sensitivity training for staff and special orientation and academic services. Many of the universities emphasise that the student must disclose their disability, provide proof of that disability, which then needs to be assessed and the subsequent accommodation will be determined upon that assessment. Generally, there does seem to be a

lack of support in terms of gaining entrance into university courses, with the student with a disability being assessed on the same level as any other prospective student. The universities in question, either state that the student must choose a course that they can „cope“ with, or that they offer counselling services to help students choose from courses that are „available“ or „suitable“ for them. Most of the universities state that the accommodation and services provided need to be reasonable and are restricted by affordability (DoE, 2009).

Sadly, it would appear that some universities“ policies see the accommodation given to students with disabilities as an advantage over other students. One particular university states that, if a student is given accommodation such as extra time for their examinations, it will be noted on their transcript, because “graduates are expected to be capable of working under pressure and within time constraints” (DoE, 2009, p. 15). The purpose or goal of this particular aspect of the policy is unclear to me, but it would appear they are trying to „level the playing field“ or eliminate any kind of perceived „advantage“.

The University of KwaZulu-Natal (UKZN) recognises that disability is a social construct, but in order to implement a disability policy that can redress past injustices and ensure equity for students with disabilities in the higher education context, a concrete working definition is needed. The UKZN defines a person with a disability, in the *Policy on Students and Staff with Disabilities* (UKZN, 2004, p. 2), as someone who is “limited or impaired in one or more functional activities which prevents full and equal academic, social and economic participation. The impairment may be permanent, recurring or transitory and may be sensory, physical, cognitive or psychological”. This definition does seem to be broad enough to encompass chronic illness as a disability.

The UKZN, like other South African universities, has put policies in place to accommodate students with disabilities, but ultimately these policies are of little use if the students do not make use of them. In order to access the accommodation made available to students with disabilities, the student first needs to disclose that they have a disability. As is discussed in greater detail below, this disclosure is complicated by a myriad of issues that can potentially act as a barrier and subtly coerce a student into maintaining silence. Chronically ill students are perhaps most vulnerable to these particular barriers, which can make them difficult to identify. This consequentially leaves them vulnerable to many of the same barriers and challenges faced by students with disabilities in general.

A South African book compiled by the Human Sciences Research Council, *Disability and Social Change* (2006), takes a closer look at learners with disabilities in higher education within the South African context. Howell (2006) explains that barriers faced by such students originate in the inequalities that shaped our history and subsequently our schooling system.

Our history has important relevance to the accessibility issues encountered by learners with disabilities, their retention rate in higher education and their academic success. In the past, inadequate provision and opportunity for learners with disabilities at schooling level negatively affected their access to higher education. Today, misinformation, ill-advice, stigmatisation and lack of support further limit the opportunities that can be accessed by learners with disabilities. In the past, students were divided along the lines of „normal“ and those who were deemed to have „special needs“. Students with disabilities were separated out from mainstream schooling into specialised schooling, which was further divided along the lines of race. These „special“ schools, and in particular black special schools, lacked the resources, opportunities and curricula to equip students for higher education, rendering them „ineligible“ (Howell, 2006).

Today, although universities are encouraged to include students with disabilities, it is also stressed that universities should only select students who they deem or judge to be able to cope with the academic demands of the specified course. This judgement is often skewed by society“s negative perceptions of students with disabilities and their capabilities. Students are guided into courses the university feels they will „cope“ with or they are discouraged from pursuing a particular course that the university feels is beyond their abilities. With the changing economy and globalisation, higher education is guided by the market to produce candidates who will effectively contribute to the economy. Students who are seen as incapable of competing and contributing in the traditional sense towards the economy are not given priority (FOTIM, 2011; Howell, 2006).

Students with disabilities have difficulty in accessing higher education due to issues inherent in the schooling system, negative attitudes and prejudiced assumptions about their abilities. This is exacerbated by lack of awareness and training amongst faculty and society in general. The lack of support and accommodation such as assistive devices and inclusive teaching and learning, flexible curricula and assessment practices within the higher education system, all create additional barriers. Due to resource constraints, higher education institutions vary

widely in the services they offer and often only focus on providing assistive or technological devices without engaging in the critical appraisal of how they teach and assess and how that may further disadvantage students with disabilities. Furthermore, support services formulated for students with disabilities are often run as a separate entity to the general academic support initiatives. This limits their reach and influence with regard to real changes within the curricula and teaching and learning methodologies that can support instead of hinder the learning of those with disabilities (FOTIM, 2011; Fuller, Bradley & Healey, 2004; Healy et al., 2006; Howell, 2006).

The effects of barriers on higher education students with disabilities can be profound. As Howell contends:

Disabled people who have managed to attend higher education institutions argue that the energy, emotional resources and levels of stress involved in dealing with the overwhelming range of barriers that confront them are extremely undermining and place them at an ongoing disadvantage to other students. This in itself forces them to perform at a level not expected from other students, and if they are unable to do this, the prevailing attitudes and prejudices towards their abilities are reinforced. (Howell, 2006, p. 170)

Although the above discussion on students with disabilities in higher education does not focus on mature adult learners per se, the experiences and barriers faced by these learners and those experienced by adult learners with disabilities can be assumed to be comparable.

2.2.4 Chronically Ill Students in Higher Education

The chronically ill student in higher education faces many of the same barriers as students with „traditional“ disabilities, but with some important differences. Wendall (2001) makes the important distinction between the healthy disabled and the unhealthy disabled, classifying chronic illness under the latter. To be disabled by illness or be disabled by, for example, blindness may both incur difficulties in learning although in different ways. She adds that, where the healthy disabled tend to be in a fixed state of „disablement“, the chronically ill are continuously fluctuating between states of disablement and able-bodiedness, making their

condition unpredictable and subsequently difficult for others to understand, believe and accommodate (Wendall, 2001).

An Australian study by Shiu (2001) on the education of students with chronic illnesses, although exclusively focused on children, provides an illuminating account of the struggles a chronically ill student faces in education. Due to the nature of their illness and the need for more intensive medical care, the resultant high rates of absenteeism impact on the academic success of a chronically ill student. Additionally, Shiu (2001) reported that it is more difficult for the student to reintegrate into the academic setting after a long term of absence. Academic performance can be adversely affected by the illness itself or by the anxiety of trying to keep up or catch up with one's peers. Difficulties in developing and maintaining friendships were also highlighted as an issue which, at a later stage, could result in low self-esteem, poor academic performance and behavioural problems. Social support, from home, school and the community, is deemed critical to the academic success of a chronically ill student and assists in the development of effective coping skills (Shiu, 2001).

The experiences of the chronically ill school going student are not dissimilar to those of a chronically ill adult student in higher education. Negative impacts on the person's development as a student, self-esteem, academic performance and social relationships hold true for adult learners, as well as their school going counterparts, although they manifest in different ways (Hammer et al., 2009; Jung, 2002; Olney & Brockelman, 2003; Sierra-Zarella, 2005; Vavouraki et al., 2009). A Canadian, feminist researcher, Karen Jung (2002), focused on the ongoing difficulties chronically ill woman in higher education face, in particular, their continuous struggle to obtain accommodation from the higher education institution itself, which impacted upon their academic performance, as well as their own sense of legitimacy and self-esteem. This was echoed by Olney and Brockelman (2003), who also earmarked how being chronically ill, and the disclosure of this status, impacted on the social relations and interactions with others. A study conducted at a Greek university concluded that students with chronic illnesses or „hidden“ disabilities struggled with absenteeism and difficulties with academic and social participation due to the effects of the illness and/or the required medical treatment (Vavouraki et al., 2009). In her own personal account, Elizabeth Sierra-Zarella (2005) confirmed many of the above findings, as did an Australian study by Hammer, Werth and Dunn (2009) and a practice brief for DePaul University concerning supporting the needs of chronically ill college students (Royster & Marshall, 2008).

The literature indicates that chronically ill students in higher education face many of the above mentioned challenges. Keeping up with academic demands whilst dealing with ill health proves to be a major barrier for those who are chronically ill (Hammer et al., 2009; Jung, 2002; Olney & Brockelman, 2003; Royster & Marshall, 2008; Sierra-Zarella, 2005; Vavouraki et al., 2009), but where those who are viewed as „traditionally“ disabled can seek accommodation, often this option becomes an issue of contention for the chronically ill student. Complex interacting issues determine if a chronically ill student will seek help or not. The „hidden“ nature of chronic illness thus complicates and influences how the student navigates their way through higher education (Fitzgerald & Paterson, 1995; Fuller, Bradley & Healy, 2004; Hammer et al., 2009; Jung, 2002; Olney & Brockelman, 2003; Royster & Marshall, 2008; Sierra-Zarella, 2005; Valeras, 2010).

2.3 Chronic Illness as a „Hidden“ Disability

As discussed in the first chapter, different types of disabilities can be termed „hidden“, such as learning, cognitive and emotional disabilities (Chalkley & Waterfield, 2001; Olney & Brockelman, 2003; Wolf, 2001), and chronic conditions such as asthma and epilepsy. The focus of this study, however, is on chronic autoimmune and fatigue-related illness. Chronic illness can remain unnoticed by others due to its lack of external features or manifestations, placing the person in a unique position, as they can choose whether to hide or reveal their condition, hence the „hidden“ quality of this particular type of disability.

Falling under chronic illnesses, autoimmune illnesses epitomise this „hidden“ aspect. As quoted in the previous chapter, autoimmune diseases are defined as follows:

Autoimmune diseases refer to problems with the acquired immune system’s reactions. In an autoimmune reaction, antibodies and immune cells target the body’s own healthy tissues by mistake, signalling the body to attack them... Autoimmune diseases can affect almost any part of the body, including the heart, brain, nerves, muscles, skin, eyes, joints, lungs, kidneys, glands, the digestive tract, and blood vessels. (National Institute of Arthritis and Musculoskeletal and Skin Diseases, 2012, p.1)

Autoimmune illnesses, such as systemic lupus erythematosus, early stage multiple sclerosis, rheumatoid arthritis, Chron's disease, and so-called „mystery“ illnesses such as chronic fatigue syndrome and fibromyalgia, are not immediately apparent to a casual observer and have similar characteristics such as inflammation, nausea, fatigue, pain and general feelings of malaise (Davidson & Diamond, 2001; Lahita & Yalof, 2005; Macintyre, 1992; Page et al., n.d.). The symptomologies of these illnesses and their subsequent impact are similar in nature and can be grouped together even though their causes, diagnostic criteria and treatment may not necessarily be the same. It may be prudent to add at this point that, although AIDS, and AIDS-related illnesses, often have chronic characteristics and can be considered a chronic illness, it is categorised as communicable and therefore it is inherently different to the chronic illnesses highlighted in this study (Colvin, 2011). Additionally, this study deliberately focuses on lesser known illnesses, as there has been a large amount of research attention on AIDS in education (Babikian et al., 2004; Beyers & Hay, 2011; Hargreaves et al., 2008; Phaswana-Mafuya & Peltzer, 2006), but very little on other chronic illnesses such as autoimmune illnesses.

Research from many different parts of the world show that, not only are chronically ill people struggling with the daily difficulties of living with a body that is ill, fatigued and in pain, but they are also having to contend with a myriad of psychological, social and cultural issues (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Laidmäe, 2012; Shiu, 2001; Valeras, 2010; Wendall, 2001). Jung (2002) elaborates further on the cultural implications for someone with a „hidden“ disability. Culture determines what is beautiful, what is normal or abnormal, what is considered disabled and abled. It influences if and how one will express pain and illness and determines what disabilities are considered legitimate, how they are recognised and what concessions or accommodation will be provided for that disability. Dominant cultural understandings of disability can create assumptions that can be challenging to those with „hidden“ disabilities.

Highlighting some of the above issues, an American researcher, Davis (2005), examines some of the misconceptions surrounding chronic illness. The „invisibility“ of chronic illness, in the eyes of society, somehow lessens the perceived seriousness of the chronic illness and its disabling effects, and according to Davis, “[p]eople whose disabilities are not generally perceived by others do not, for that reason alone, find it easier to minister to themselves or to engage productively and effectively in the world without having to endure pain, discomfort,

and exhaustion” (p. 154). The general assumption that the „invisibility“ of this type of disability protects the individual from stigmatisation associated with more visible disabilities is flawed. “Though not as easily stigmatized in obvious or familiar ways, persons with invisible disabilities are subject to forms of rejection, humiliation, and social disapproval that are importantly similar” (p. 154). Davis (2005) highlights that, for the chronically ill, making the decision to reveal their disability in order to access help, and being subjected to a process where they must convince others of their legitimacy and provide proof of their disability, can be highly stressful and have its own psychological impact. As Davis (2005) notes, stress is unpleasant in itself, but it can have a far more profound effect on those who are chronically ill. The lowered immunity and increased fatigue caused by stress eventuates in additional strain on a body that is already ill, fatigued and in pain. Besides the impact on health, Davis (2005) explains that “having to reveal that one is disabled and having to make requests for assistance or accommodation that are often met with scepticism and hostility can visit steep psychic and moral costs upon persons with invisible disabilities” (p. 155). Much of what Davis (2005) revealed about stress, guilt, pain, the effects of illness and other social and psychological issues of those with invisible disabilities was voiced in a much earlier Australian study by Fitzgerald and Paterson (1995) and echoed in other research by Jung (2002), Laidmäe (2012), Shiu (2001), Valeras (2010) and Wendall (2001), amongst others.

It would seem from the above literature that defining chronic illness and, in this study, autoimmune illness as a disability, would be an obvious and simple choice. The limitations, obstacles and difficulties faced by those who are chronically ill fit within most definitions and explanations of disability, including that of the World Health Organisation (WHO), detailed in chapter one.

Chronic illness clearly has the potential to limit activity and restrict participation, and thus resonates with the WHO definition. For example, a student with an illness characterised by fatigue, might not be able to climb stairs, access a tutorial venue and pay attention for an extended period. This would restrict participation in a tutorial class. However, defining chronic illness as a disability can be problematic. This is addressed in more detail below.

2.3.1 Medical and Social Models of Disability

There are two major models of viewing and defining disability, namely, the medical model and the social model. The medical model situates disability within the individual. It “ultimately reduce[s] the origins of disability to individual pathology” (Llewellyn & Hogan, 2000, p. 158). Disability, according to this model, is a physical impairment generally caused by trauma, illness or other health conditions and is primarily something that needs to be cured or fixed. The medical model views disability as something that is abnormal and locates it within the individual. This understanding of disability carries negative connotations, viewing someone who is disabled as broken, un-whole and lacking.

The social model of disability arose as a critical reaction to the medical model and has its origins in the disability movement. People with disabilities reject the notion that they are abnormal. The social model postulates that disability does not stem from a person with a disability, but rather it is the outcome of an oppressive society (Oliver, 1986). Llewellyn and Hogan (2000) add that “the social model emphasises that individuals who are different by virtue of an impairment find they are oppressed by a society obsessed with concepts of normality” (p.160). This model situates the problem of disability in society itself and not in the individual. The social model does not see the person’s impairment as disabling, but rather ascribes this to the environment. Thus, according to the social model, restructuring society and the environment, and eliminating disabling barriers, would ultimately remove disability.

The social model has been criticised though (Dewsbury, Clarke, Randall, Rouncefield & Sommerville, 2004; Shakespeare & Watson, 2001; Thomas, 2004; Waddell & Aylward, 2010; Williams, 1999), as tending to simplify disability and its causes, and as touting that through societal change, disability can be reduced or even removed completely. The social model minimises the role of the body in disability and the experience of pain and limitation that impairment can bring. Even if all societal barriers are removed, this would have little impact on a person whose impairment is characterised by chronic pain (Shakespeare & Watson, 2001). This criticism is pertinent to the issue of chronic illness where chronic pain is often a feature (Wendall, 2001). It would be naïve to think that if all societal barriers were removed, even if at all possible, an impairment caused by chronic pain would cease to impair and disable that individual (Dewsbury et al., 2004; Shakespeare & Watson, 2001; Thomas, 2004; Waddell & Aylward, 2010; Williams, 1999).

Wendall (2001) highlights a critique by Liz Crow, a British feminist disability activist, who explains that, due to the social model's emphasis on prejudice and discrimination as the primary cause of disability, there is a reluctance to recognise impairment and its connection with the body due to fears of undermining the work and progress made to move away from the medical model's understanding and ways of treating disability. This results in silence around issues of impairment, a lack of acknowledgement and exclusion from disability politics. This silence, in turn, creates prejudice and discrimination of its own, leaving those with impairments little room to express their experiences of disability and the need for help and accommodation. Acknowledging impairment as a disability has become in itself taboo.

There is resistance to defining chronic illness as a disability. The tireless work of the social model and the disability movement to separate disability from illness and break away from the medicalisation of disability has contributed to the exclusion of those who are chronically ill from disability politics (Jung, 2002; Wendall, 2001; Williams, 1999). However, as Wendall (2001), Williams (1999) and Jung (2002) explain, chronic illness is disabling in the sense that it directly and negatively impacts on a person's functioning and participation in society and the insistence of the disability movement in distancing itself from impairment in fact alienates those who are chronically ill from the recognition, validation and accommodation they need. Chronic illness can severely limit or impair functioning and participation in life activities, but there are those who are chronically ill who will not identify themselves as disabled for various reasons such as issues of identity, validation, legitimisation and fear of stigmatisation from both disabled and able-bodied members of society (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Laidmäe, 2012; Shiu, 2001; Valeras, 2010; Wendall, 2001).

In order to include and accommodate people with chronic illness in disability politics, it is essential that impairment is recognised and acknowledged. Recognition of the role of the body and impairment as a source of disability and the importance of medical interventions need to be openly discussed without other agendas in place that may hamper or undermine the seriousness and negative impact impairment can create. An approach that recognises not only "medically-based descriptions of our bodies/minds but also our experiences of our bodies/minds...the effects they have on our activities, the feelings they produce, and any concerns about them that impaired individuals might have", is needed (Wendall, 2001, p. 23).

2.3.2 An Interactive Model of Disability

A more encompassing model is needed in order to understand the complexity of disability. A disability model that includes not only the social and medical aspects of disability, but also takes into account the psychological, political and cultural aspects that impact on the experiences of a person with a disability, would go some way towards developing a multifaceted approach to understanding disability (Shakespeare & Watson, 2001). Rule and Modipa (2011), who drew this model from Shakespeare (2006) in a study on disabled adult learners, proposed a holistic interactional model of disability. They provide an in-depth description of this approach.

This view is holistic in the sense that it strives to accommodate not only biological aspects (medical model) and sociopolitical aspects (social model) of disability but also the cultural and psychological aspects within the lived bodily experiences of persons with disabilities. It is interactional in that it interrogates the relations among these aspects in context. Within this model, therefore, disability is not a purely individual or social phenomenon but arises from the often complex relationship among various factors in a dynamic context. (Rule & Modipa, 2011, pp. 4-5)

The interactional model provides a fitting theoretical framework for my study regarding disability. As one can see from the literature review, disability comes from a myriad of sources. Psychological and social factors such as identity, stigmatisation and culture impact on disability; biological issues, such as the impairments of the body, also play a role. All of these factors cannot be sufficiently explained under just one of the traditional models such as the social model or medical model. The interactional model provides a more holistic view that encompasses the lived experiences of disabled persons and it provides the space for chronic illness to be recognised and accounted for within a disability framework.

The interactional model, proposed by Shakespeare (2006), draws upon useful aspects from a number of theorists, views and models. This provides a foundation for an approach that is multifaceted and holistic. It “avoids the danger of trying to fit the complexities and nuances of life into an over-rigid structure or system” (Shakespeare, 2006, p. 54). Shakespeare (2006) argued that the failure of the social model to successfully conceptualise and reconcile the different features and attributes of disability necessitated the need for a model that could do

just that. The social model, as a structural and social approach, emphasises barriers and oppression as the main mitigating feature of disability but, as pointed out by Shakespeare (2006) and numerous other critics, it fails to acknowledge the role of impairment in disability. Additionally, the social model fails to “encompass the range of different impairment/disability experiences” (Shakespeare, 2006, p. 55).

The interactional model argues that disability is an interaction between structural and individual features and thus disability should not be reduced to either a result of a deficit or a structural disadvantage. Individual intrinsic factors such as personality, personal strengths and weaknesses and the severity of the impairment interact with external contextual factors such as sociocultural attitudes and support, producing or creating disability. Although the interactional model recognises barriers such as prejudice as disabling, these types of barriers are seen as only a part of the disability experience. Impairment is highlighted and is recognised as an important contributing factor to disability, but once again, it is emphasised that this model is non-reductionist and thus, the role of impairment cannot overshadow other contributing factors to disability. Shakespeare (2006) explains:

It is always the combination of a certain set of physical or mental attributes, in a particular physical environment, within a specified social relationship, played out within a broader cultural and political context, which combines to create the experience of disability for any individual or group of individuals. (Shakespeare, 2006, p. 58)

The interactional model is able to provide a basis for understanding this complex interplay and allow for a range of varied disability experiences, including impairment and chronic illness (Shakespeare, 2006). Shakespeare (2006) points out that the interactional model allows for variations in the disability experience such as those who have impairments that are so disabling that the removal of barriers would do very little to eliminate their disablement and those that have impairments which cause minimal constraints but the reaction of society to their impairment creates ostracism, oppression and hardship for the person in question.

Writing from a South African perspective, Schneider (2006) echoes much of the above discussion. She argues that in order to understand and conceptualise the disability experience one needs to look at both environment and internal personal elements. Disability needs to be

understood in context. This environmental model has many similarities to the *International Classification of Functioning, Disability and Health* (ICF) biopsychosocial model, which reiterates that disability, needs to be understood as a complex interaction between environment (social, physical, cultural etc.) and personal factors. Schneider (2006) explains that “[d]isability can no longer be seen as a static feature of an individual but rather as a dynamic and changing experience determined by the changing nature of the environment” (p. 8). These perspectives are in keeping with Shakespeare’s interactional model. Although these three models’ basic premise is the same, Shakespeare extends his model by looking at impairment and chronic illness more closely.

In closing, Shakespeare’s understanding and conceptualisation of disability, which includes impairment, chronic illness and a range of multifaceted and diverse disability experiences, provide a fitting framework for understanding the experiences and challenges faced by adult learners with „hidden“ disabilities in the higher education context.

2.4 Disability, Identity and Social Context

The nature of a „hidden“ disability, such as chronic illness, influences the disabled identity and the consequences thereof (Olney & Brockelman, 2003; Valeras, 2010). Studies focusing on students with „hidden“ disabilities have revealed that some students have incorporated disability as a core aspect of their identity, but the degree to which this disabled identity is salient is dependent on the situation. This is succinctly explained by Olney and Brockelman, in an American study, who reported that “students went through the repeated process of sense making while simultaneously negotiating their roles and identities with family members, friends, professors, and employers...[i]ndividuals viewed their disabilities as context-dependent and variable” (2003, p. 39). Chronically ill participants in Valeras’ study (2010), in contrast, balked at the idea of calling themselves disabled or having their condition termed as a disability. They either expressed embarrassment, claiming that their condition was not disabling enough to be considered a disability, or they felt that there were too many negative consequences with identifying themselves as disabled (Valeras, 2010).

The social context, perceptions and definitions of disability all impact on whether students with „hidden“ disabilities will define themselves as disabled and, in turn, whether they will disclose a disabled identity to access the help that is provided by the university.

In the United Kingdom, Fuller, Bradley and Healy's (2004) study revealed that students differed in their willingness to disclose their disabilities. Although the study revealed some of the barriers these students faced in learning, such as issues in assessment and access to information, little focus was given to the underlying psychological and social aspects that impact and guide students' disclosures, coping skills and help-seeking behaviour (Fuller, Bradley & Healy, 2004).

The study conducted by Olney and Brockelman (2003) delves more deeply into the psychological, social and cultural aspects of tertiary students' lives as they negotiate their way through university. They particularly focus on how students with „hidden“ disabilities managed the perceptions of themselves and others in relation to their disability and how these students' shifted from a disabled identity to an able-bodied identity, depending on the context. This study does provide insight into the lives of tertiary students with „hidden“ disabilities, but it particularly focuses on psychiatric and cognitive disabilities. Although the „hidden“ aspect of cognitive and psychiatric disability is much the same as someone who has a chronic illness, there are still some differences. It was found that a contributing factor for non-disclosure amongst these students was the social stigma attached to cognitive or psychiatric impairments (Olney & Brockelman, 2003). The stigma attached to chronic illness is different and this may result in different consequences (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Olney & Brockelman, 2003; Wendall, 2001).

A strong recurring theme in the above mentioned literature is the negativity surrounding the disabled identity. Disability represents something that is less than whole, broken and different. It is a “socially devalued self identity” (Fitzgerald & Paterson, 1995, p. 15). These negative perceptions are closely linked to how disability is defined and consequently perceived by both disabled and able-bodied persons.

2.4.1 The Dialogical Self Theory

As indicated above, the interactional model provides a way of framing disability in this study. In addition, the Dialogical Self Theory is able to provide a framework in which to understand the complex, context-dependent and shifting construction of identities prevalent in the above literature.

Due to the complexity of the Dialogical Self Theory, I adhere closely to the conceptual explanations and development of the theory provided in the articles and books written by the below mentioned authors. Drawing on their expertise, I endeavour to provide an overall view of the theory at hand. The following definition of the self by Hermans (2001) provides a good starting point for the discussion that follows:

Inspired by the original Jamesian notions of the self and by the Bakhtinian polyphonic metaphor, Hermans, Kempen and Van Loon (1992) conceptualized the self in terms of a dynamic multiplicity of relatively autonomous *I*-positions. In this conception, the *I* has the possibility to move from one spatial position to another in accordance with changes in situation and time. The *I* fluctuates among different and even opposed positions, and has the capacity to imaginatively endow each position with a voice so that dialogical relations between positions can be established. The voices function like interacting characters in a story, involved in a process of question and answer, agreement and disagreement. Each of them has a story to tell about his or her own experiences from his or her own stance. As different voices, these characters exchange information about their respective *Me*'s, resulting in a complex, narratively structured self. (Hermans, 2001, p. 248)

The Dialogical Self theory encapsulates the idea of how one person may have many selves, or *I*-positions, in different contexts and in relation to different people; in essence, a dynamic society of mind that interacts spatially, on an external and an internal level (Bertau & Gonçalves, 2007; Hermans, 2001, 2003, 2013, 2015; Hermans & Hermans-Konopka, 2010a; Thomson, 2006).

The Dialogical Self Theory is developed from the work of James on the self and Bakhtin on dialogue. James (1890, cited in Hermans, 2001) proposed that an individual has an internally experienced subjective identity, „*I*“, and an objective identity, „*Me*“, which are characterised by their societal roles. This *I*-position or the „Self-as-knower“ is experienced as one's sense of self which has a sense of volition or ability to choose and exercise free will and is relatively continuous and separate from others. This is in contrast to the objective self or „Self-as-known“, that can manifest in multiple „*Me*'s“ or social selves that are not necessarily congruous. There is not an inflexible distinction between the self and other; rather, the self extends into and incorporates aspects of the other into its identity. This shift from „*I*“ to „*me*“

and „mine“ is significant, in that the self extends outwards and incorporates and internalises the external environment; my mother, my dogs, my job, my house, my friends all become part of a person’s identity. Bakhtin’s (1973 as cited in Hermans, 2013) concept of the polyphonic novel emphasised that each of these „I“ and „Me“ positions become characters, imaginatively endowed with their own voices, some more dominant or salient than others, that have their own narratives, dialogues, interactions, agreements and disagreements (Bertau & Gonçalves, 2007; Hermans, 2001; Hermans, 2003; Hermans, 2013; Hermans, 2015; Hermans & Hermans-Konopka, 2010a; Thomson, 2006).

Building upon James’ multiplicity of self and Bakhtin’s multiple dialoguing voices, the Dialogical Self Theory postulates that there is a constant dialogue amongst a person’s many I-positions and the other (which can be considered as another „I“) which creates multiple selves. Hermans defines the self as a “dynamic multiplicity of positions or voices in the landscape of the mind with the possibility of dialogical relations between these voices or positions” (Hermans & Hermans-Konopka, 2010a, p.81).

A person, through dialogue, is constantly negotiating and renegotiating roles, selves and positions. These multiple selves are not only internal (I-as-wife, I-as-hard worker, I-as-loyal friend) but are external (my husband, my job, my friends), in tension and constantly evolving and changing as the internal interacts and dialogues with the external (Bertau & Gonçalves, 2007; Hermans, 2001, 2003, 2013, 2015; Hermans & Hermans-Konopka, 2010a).

[A]ll these positions (internal and external) are I-positions because they are part of a self that is intrinsically extended to the environment and responds to those domains in the environment that are perceived as „mine“ (e.g. my friend, my opponent, my place of birth). (Hermans, 2001, p. 252)

In addition to social roles creating different I-positions, emotions too, can create temporary I-positions. Emotions are part of the foundational and organising principle of the self. Emotions and the self are interconnected and „bi-directional“, meaning that emotions can impact upon the self and the self is able to change or confirm those emotions. Not only do we position ourselves in an emotion such as I-as-sad, we are also positioned by our emotions (Hermans & Hermans-Konopka, 2010a, 2010b). Hermans and Hermans-Konopka (2010a) provide the following example:

We can become irritated even when we consciously want to be friendly and we can feel nervous and anxious even when we cannot find any “objective” reason for that. Apparently, the *I* is forced to be receptive when emotions come up in the self and “occupy” the space of the self. (p. 260)

Different I-positions can elicit different emotions and different emotions can create different I-positions, both externally and internally (Hermans and Hermans-Konopka, 2010a).

Emotions are not purely internal processes, but parts of a highly dynamic social and societal process of positioning. Depending on the positions in which people find themselves, particular emotions are expected to emerge, whereas others are expected to be absent or suppressed. (p. 257)

Emotions position us socially and personally. The saliency of the emotion, social context, adopted internal and external social I-positions and their associated role expectations will influence this process of positioning.

People and objects in the environment become external positions if they are relevant to one or more of a person’s internal positions, for example, my friend who is in trouble becomes important to me because I see myself as a loyal and helpful friend. Internal positions are created from their relevancy to and interaction with one or more external positions, for example, I feel that I am a wife because I have a husband. These positions can come into conflict if one’s I-positions such as I-as-caring-wife comes into conflict with I-as-dedicated-student, for example, when an exam is pending and you need to study but your husband is sick and needs you to take care of him (Bertau & Gonçalves, 2007; Hermans, 2001, 2003, 2013, 2015; Hermans & Hermans-Konopka, 2010a). The saliency of particular I-positions is dependent on the identity’s sensitivity to contextual external influences and the internal struggle of power and dominance as certain selves or I-positions take precedence over others (Batory, 2010).

The Dialogical Self theory also highlights the interconnectedness of motivation and identity. Building upon dialogicality and identity construction, Batory (2010) explains how identity is moulded by motivational influences. Batory (2010, p. 47) notes that there are six “identity

motives” which are motivational principles that influence identity construction; namely, self-esteem, efficacy, continuity, distinctiveness, belonging and meaning. She explains these identity motives in more detail:

Self-esteem is conceived as a motivation to preserve and strengthen a positive perception of one’s self. Efficacy refers to the searching for feelings of competence and control. Continuity relates to the need to preserve subjective sense of continuity across time and situation (however this continuity does not exclude change).

Distinctiveness refers to searching for a sense of differentiation from others, on the individual and social level. Belonging concerns the motivation to maintain and enhance feelings of closeness or acceptance by other people. Meaning is responsible for striving for the purpose in one’s life. (Batory, 2010, pp. 47-48)

She explains that identity elements that fulfil these six motives are favoured in one’s identity, thus motives play an important role in shaping and guiding the I-positions a person adopts.

Culture and the self are not seen in isolation, but rather in a dynamic dialogical process that repositions, changes or even creates new I-positions and a multiplicity of selves (Hermans, 2001, 2003, 2013, 2015; Hermans & Hermans-Konopka, 2010a; Valsiner & Han, 2008). As this study involved South African universities and higher education institutions, it was crucial to be cognisant of the African collective culture and understanding of identity. The Dialogical Self Theory not only focuses on „I“ and „me“ positions but it also incorporates culture, the „other“ and the collective voice as interrelated aspects of identity (Bertau & Gonçalves, 2007; Hermans, 2001, 2003, 2013, 2015; Hermans & Hermans-Konopka, 2010a; Valsiner & Han, 2008) which are pertinent to African identity (Meyer, Moore & Viljoen, 2003). The dialogical self comprises a dynamic interaction of individual and collective voices “representing social groups, communal worldviews and other shared perspectives” (Batory, 2010, p. 46). As these multiple voices interact, question, position, counter-position, disagree and reinvent themselves through dialogue and story, a dynamic narratively structured self is created (Hermans, 2001, 2003, 2013, 2015; Hermans & Hermans-Konopka, 2010a). This understanding of the self and construction of identity accommodates the African collective identity.

An additional aspect to Herman's theory is the concept of the meta-position. Meta-positions afford "an overarching view that allows one to consider different positions simultaneously, including their relevant linkages...they permit and facilitate the *organization* of the self beyond the spur of the moment and allow a more encompassing view on self and world" (Hermans, 2013, p. 86). A meta-position allows the self to „rise above“ or separate from the other positions of the self, reflect on them, create a dialogue among them and learn about itself.

In relation to the present study, a chronically ill adult student might have to negotiate and relate multiple self-positions, for example, I-as-ill, I-as-student, I-as-parent, I-as-aspiring, I-as-depressed, I-as-resourceful, I-as-abled, I-as-disabled and so on. Meta-positions have the potential to assist in creating an alliance between disparate I-positions, facilitating acceptance of an inherently complex and multifaceted chronically ill self. Dialogical Self Theory provides a lens for understanding and analysing these and other possible positions in relation to identity construction. Hermans' idea of positioning includes the active dimension of positioning oneself, as well as the passive dimension of being positioned by others and by society. There might be a tension between these active and passive, and internal and external positionings, for example, I-as-student, I-as-chronically ill versus my university, my family, and so on.

In sum, the Dialogical Identity theory postulates the self as multiple, fluid, context-dependent and evolving, providing a framework and lens to understand the changing identities of people with „hidden“ disabilities and assisting in the analysis of the data.

2.5 Disclosure or Non-Disclosure

The disclosure or non-disclosure of students with „hidden“ disabilities is complex and is influenced by numerous factors. Factors such as help-seeking behaviour, coping strategies and perception management can help explain the mechanisms, motivations and influences behind disclosure or non-disclosure, but cannot be considered as an all-inclusive explanation of the behaviour. A comprehensive discussion and analysis of all contributing factors that determine disclosure or non-disclosure behaviour is beyond the scope of this dissertation and thus only a few prevalent factors, highlighted in the relevant literature, have been selected for further discussion.

People differ in their willingness to seek help and the decision to seek it is influenced by a person's attitude towards help-seeking, their intentions and their perceived costs and benefits associated with that help-seeking (Cornally & McCarthy, 2011; Karabenick, 2003; Kitsantas & Chow, 2007; Kulkarni, 2012; Mäkitalo-Siegl & Fischer, 2011; Roussel, Elliot & Feltman, 2011; Trammell et al., 2007; Wacker & Roberto, 2013; Wilson, Deane, Ciarrochi & Rickwood, 2005). Within the academic context, research has shown that help-seeking is an important strategy in facilitating academic success (Karabenick, 2003; Kitsantas & Chow, 2007; Mäkitalo-Siegl & Fischer, 2011; Roussel et al., 2011; Shields, 2001; Trammell et al., 2007; White & Bembenuddy, 2013). Adaptive help-seeking behaviour can be utilised as an important coping mechanism and is regarded as an attribute of a self-regulated learner (Karabenick, 2003; Mäkitalo-Siegl & Fischer, 2011; Shields, 2001; White & Bembenuddy, 2013).

In education, help seeking has been associated with motivation, self-regulation, goal orientation, and self-efficacy. Learners, who seek help while disregarding threat to self-esteem, tend to be highly successful and adapt better to their environment than learners who avoid seeking help. (White & Bembenuddy, 2013, p. 1)

Across varying contexts, certain characteristics, such as gender and age, seem to influence whether a person will engage in help-seeking behaviour (Cornally & McCarthy, 2011; Koydemir-Özden & Erel, 2010; Möller-Leimkühler, 2002; Oliver, Pearson, Coe & Gunnell, 2005; Rickwood, Deane, Wilson & Ciarrochi, 2005; Wacker & Roberto, 2013; Wilson et al., 2005). Literature on help-seeking behaviour in people with mental health issues shows that women are more likely than men to seek help, and older persons more so than their younger counterparts (Koydemir-Özden & Erel, 2010; Möller-Leimkühler, 2002; Oliver et al., 2005; Rickwood et al., 2005; Wilson et al., 2005). Additionally, younger persons tend to be more comfortable seeking informal help rather than utilising formal resources (Koydemir-Özden & Erel, 2010; Oliver et al., 2005; Rickwood et al., 2005; Wilson et al., 2005). This pattern of age and gender differences in help-seeking behaviour is mirrored in other academic and non-academic contexts, with the exception of much older adults in a non-academic context, who tend to engage less in help-seeking behaviour due to, amongst other reasons, the desire to maintain independence or lack of information about available resources (Cornally & McCarthy, 2011; Wacker & Roberto, 2013). There does seem to be some evidence that older

students are more comfortable with seeking help and using formal resources due to their motivation, prior experience and strategies for learning (Howell, 2004; Karabenick, 2003; Koydemir-Özden & Erel, 2010; McGivney, 2004; Richardson & King, 1998; Shields, 2001). Besides fear of social embarrassment, fear of stigmatisation is prevalent in research on help-seeking behaviour of persons with mental health issues and disabilities in general (Hunt & Eisenberg, 2010; Kulkarni, 2012; Möller-Leimkühler, 2002; Oliver et al., 2005; Rickwood et al., 2005; Trammell et al., 2007).

The above literature shows that factors such as the help-seeking context, the nature of the problem, motivation, learning strategies, lack of information about helpful resources, perceived benefits and threats to one's sense of autonomy, independence, control and self-esteem all influence help-seeking behaviour (Cornally & McCarthy, 2011; Hunt & Eisenberg, 2010; Karabenick, 2003; Kitsantas & Chow, 2007; Koydemir-Özden & Erel, 2010; Kulkarni, 2012; Möller-Leimkühler, 2002; Oliver et al., 2005; Rickwood et al., 2005; Roussel et al., 2011; Trammell et al., 2007). It is a complex and variable behaviour that is context-dependent and perception based.

Although there are a number of different theories such as the Threats-to-Self-Esteem Model or Reactance Theory (Wacker & Roberto, 2013) used to explain help-seeking behaviour, the above literature seems to point, on its most basic level, to decision making processes based on a perceived cost-to-benefit ratio (Cornally & McCarthy, 2011; Hunt & Eisenberg, 2010; Karabenick, 2003; Kitsantas & Chow, 2007; Kulkarni, 2012; Mäkitalo-Siegl & Fischer, 2011; Möller-Leimkühler, 2002; Roussel et al., 2011; Trammell et al., 2007; Wacker & Roberto, 2013; Wilson et al., 2005). This perceived cost-to-benefit ratio appears to fit with the processes a person with „hidden“ disabilities goes through when deciding if they should disclose in order to access help. Closely tied to help-seeking behaviour is perception management.

Perception management has been highlighted as an important mediating factor for disclosure or non-disclosure and is linked with identity (Olney & Brockelman, 2003). Olney and Brockelman's study found that students actively managed perceptions of themselves in order to control and decrease negative perceptions others may have of them and to maintain their own positive self-perceptions. There is a constant negotiation and weighing up of personal needs against possible consequences when deciding whether to disclose or not. Olney and

Brockelman (2003) explain that “self-disclosure is a contextual act that depends upon many factors including situation, life stage, familiarity, and necessity” (p. 36). This phenomenon is not exclusive to the Olney and Brockelman study or students, but also appears, if not explicitly stated, in other studies focusing on participants with „hidden“ disabilities (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Olney & Brockelman, 2003; Valeras, 2010). It seems that perception management is employed as a tactical skill to safe-guard the self (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Olney & Brockelman, 2003; Valeras, 2010).

Coming out of the disability closet is a personal decision that has serious repercussions for the individual in terms of relationships and opportunities. It is a decision that must be made repeatedly based on an intricate web of perceived beliefs and consequences. (Olney & Brockelman, 2003, p. 49)

Therefore, it is not a simple task for those with „hidden“ disabilities to get help. The students in Olney and Brockelman’s (2003) study revealed that they were very much aware that once others knew of their disability it would change and influence how others behaved towards them. This disclosure and subsequent impact on behaviour is evident in other literature too (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Olney & Brockelman, 2003; Valeras, 2010; Wendall, 2001). Many of the students in the various studies had to provide evidence of their disability in order to access help or social support (Jung, 2002; Olney & Brockelman, 2003). Revealing their disability impacted on and changed their relationships with others. Additionally, the „hidden“ nature of their disability not only caused others to doubt the validity of their disability, but it also bred self-doubt and a questioning of their own legitimacy (Jung, 2002; Olney & Brockelman, 2003). This attitude impacted on their sense of self-worth and influenced their decisions to access help and accommodation (Jung, 2002; Olney & Brockelman, 2003).

Students with „hidden“ disabilities felt that people with visible disabilities appeared more legitimate and were more likely to be believed and helped (Jung, 2002; Olney & Brockelman, 2003). Some of these students struggled with a deep-seated need to prove themselves to others as worthy, which placed them under a tremendous amount of pressure to perform despite their disabilities. This attitude impacted on their sense of self-worth and influenced their decisions to access help and accommodation (Jung, 2002; Olney & Brockelman, 2003).

It was not always easy for students to get the help they needed. For several of them, a lack of assertiveness, difficulty advocating for themselves, or concern about the judgments of others appeared to present barriers to requesting appropriate accommodations. (Olney & Brockelman, 2003, p. 44)

An Australian study, outside of the educational context, conducted research on „hidden“ disabilities, focusing on two groups of participants who had either multiple sclerosis or temporomandibular joint syndrome (Fitzgerald & Paterson, 1995). The authors explained that people with „hidden“ disabilities, in their everyday lives, have to contend with a disability that has not yet manifested itself. The „hidden“ nature of these disabilities not only causes others to doubt the validity of their disability, but it also breeds self-doubt and a questioning of their own legitimacy. The participants expressed fears, and in some instances real experiences, of being disbelieved, accusations of being lazy or malingering, making the decision to disclose all the more difficult. Fitzgerald and Paterson (1995) also found that culture influenced whether someone would disclose or not. In some cultures it is seen as a sign of weakness to let others know that you are sick or in pain. Fitzgerald and Paterson also found that these people went to extreme lengths to satisfy their obligations and expected roles, often overcompensating in order to preserve the image of a complete and healthy identity. This overcompensation and a sense of „I must just pull myself together and get on with it“ is echoed in literature on students with „hidden“ disabilities (Jung, 2002; Olney and Brockelman, 2003). A more recent study by Valeras (2010) confirmed many of the same issues highlighted in the above literature. These behaviours and attitudes contribute towards disclosure or non-disclosure of a „hidden“ disability and subsequently affect how well someone with a „hidden“ disability may cope with day to day student life.

Disclosure is a complex phenomenon with multiple factors that extend beyond help-seeking behaviour, coping skills and perception management. The above discussion is not exhaustive, but rather it is an analysis of some of the factors highlighted in the literature surrounding the issue of disclosure.

2.7 Conclusion

In closing, there seems to be a common thread of issues that surface when reading through the relevant literature. Chronic illness is disabling and surrounding this issue are complex interacting aspects of identity, social context, disclosure, stigmatisation, legitimacy and perception. These aspects profoundly impact on how a student will cope in higher education. Subsequently, this myriad of compounding and interlinking factors and issues requires a multifaceted analytical approach. Thus, I endeavoured to provide a holistic, amalgamated theoretical framework that draws upon the three theories detailed above, which can provide a lens to understand my study and interpret the data.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1 Introduction

A research methodology provides an explanation and justification of how the research was conducted, the methods that were used and why those particular methods were used (Rajasekar, Philominathan, & Chinnathambi, 2013). A researcher needs to design a clear and systematic methodology which ensures that the research methods employed are suitable for, and in keeping with, the aims and underlying assumptions of the research study. The choice of particular research methods is as important as the assumptions underpinning these methods, as they ultimately have bearing on their suitability in the research study.

This methodology chapter provides an overview of the strategies, research design, sampling techniques and philosophical assumptions underpinning the research. I used a qualitative style and narrative approach, guided by the philosophical assumptions of the interpretive paradigm, supporting and guiding which data collection methods I chose to use and subsequently, how the data were analysed. This chapter provides an in-depth discussion of the above mentioned aspects.

3.2 Research Paradigm

For the purposes of this study, I chose an interpretive paradigm. This provided me with a framework that enhanced and supported an exploratory, descriptive study utilising narratives as a source of insight and knowledge building.

Paradigms are patterns “of thinking based on shared assumptions or collective awareness that is predominant in a society and affects the way individuals perceive and respond to the world” (O’Leary, 2007, p. 185). Paradigms govern the assumptions and ways researchers understand the world around them, such as the nature of being, what is „reality“ and how it is made up (ontology); the nature and creation of knowledge and the connection between the knower and the known (epistemology); the values that underlie and inform the research (axiology); and what practical methods can be used to understand or reveal this knowledge (methodology) (Guba & Lincoln, 1994; Nudzor, 2009; Terre Blanche & Durrheim, 2006).

Interpretivism arose as a critical reaction to the positivist worldview, prevalent in the natural or „hard“ sciences, which makes certain assumptions about knowledge and truth as objective and independent from the social reality being studied (Nudzor, 2009; Terre Blanche & Durrheim, 2006). A positivist perspective “assumes that social reality is made up of objective facts that value free researchers can precisely measure and use statistics to test causal theories” (Nudzor, 2009, p. 116). This worldview can be problematic within the realm of the social sciences, as its assumptions and methods were developed for the natural sciences. Social research, at its core, studies humans, their beliefs and worldviews, which are often subjective, socially constructed and not always observable; these aspects are in direct contravention to the tenets of positivism (Nudzor, 2009; Terre Blanche & Durrheim, 2006). In contrast to positivism, interpretivism maintains that there is no objective truth or reality; rather, the world, truth and knowledge, as we understand it, are created and shaped by our own beliefs, perceptions and preconceived notions. This socially constructed reality can best be understood through the worldviews and perceptions of people and their interpretations thereof (Lewis-Beck et al., 2004; Nudzor, 2009; Terre Blanche & Durrheim, 2006).

The study of social phenomena requires an understanding of the social worlds that people inhabit, which they have already interpreted by the meanings they produce and reproduce as a necessary part of their everyday activities together. Whereas the study of natural phenomena requires the scientist to interpret nature through the use of scientific concepts and theories, and to make choices about what is relevant to the problem under investigation, the social scientist studies phenomena that are already interpreted. (Blaikie, 2004, p. 509)

Disability is often researched within a critical paradigm which emphasises power relations and analysis of structures of oppression. The critical paradigm’s main purpose is to work towards transformation of inequity; it requires action, not simply observing and interpreting the particular phenomenon of interest (Babbie & Mouton, 2001). This paradigm is particularly fitting when viewing disability through the lens of the social model. However, because this study was exploratory in nature with the intention of providing a more descriptive narrative of the lives of these particular students, I felt an interpretive paradigm was more fitting. The interpretive paradigm “argues that the core of understanding is learning what people make of the world around them, how people interpret what they encounter, and how they assign meanings and values to events or objects” (Rubin & Rubin, 2011, p. 19).

This paradigm provided a platform for this study, which recognised and privileged the perceptual understandings and narratives of the participants, which in turn, provided better insight into the experiences and daily challenges encountered by adult students with „hidden“ disabilities. Through narrative inquiry as a research methodology, these students were afforded the opportunity to tell their own stories, as they saw it.

3.3 Style

3.3.1 Qualitative: Type of Data and How to Analyse it

Here, the term „style“ refers to the orientation of the study towards data and its analysis. A basic distinction between qualitative and quantitative research is that qualitative tends to focus on words, textual meanings, interpretations and such with the use of analytic tools such as thematic analysis, whereas quantitative research predominantly works in the realm of numbers, measurements and statistical analysis (Babbie & Mouton, 2001).

Qualitative research provides a rich, deep understanding of how people think, feel, perceive, interpret and interact with others and themselves. The general assumption is that people have an active role in constructing their social reality through meaning making and interpretation. Research methods should endeavour to reveal these processes (Boeije, 2010). Qualitative research affords a richness and depth that reveals the detailed and intricate experiences of people (Creswell, 2009; Hatch, 2002). Within disability research, “qualitative studies tend to provide more detail about the uniqueness of the students“ disabling conditions than do quantitative studies” (Avramidis & Smith, 1999, p. 30). Therefore, a qualitative style was appropriate for the context of my study, as I wanted to gain a better understanding of the lived experiences and perspectives of adult learners with „hidden“ disabilities.

Although it may seem that qualitative and interpretive are one and the same, they are different. An interpretive paradigm is a philosophy with particular assumptions and beliefs about ontology, epistemology and axiology, whereas qualitative research denotes a particular methodology and style of research. A qualitative style can be used in different paradigms. Perhaps the confusion comes from there being no unanimous “definition of qualitative research. In the literature of social science and applied professional fields, such terms as interpretive, naturalistic, constructivist, ethnographic, and fieldwork are variously employed

to designate the broad collection of approaches that we call simply qualitative research” (Hunt, 2003, What is qualitative research?, para. 1). In literature, a distinction between qualitative and interpretive is not always drawn, but they do differ. In the context of this study, interpretivism is used as a broad philosophical framework that underpins a qualitative research style. Adopting a qualitative style within an interpretive framework creates a coherent and complimentary approach and philosophy for research that is centred on gaining a deeper understanding of human experience, perception and worldview.

As with an interpretive paradigm, the qualitative discipline highlights the role of researchers and their own humanness as an integral and interconnected part of research. A researcher cannot separate his or herself from the world as an objective, impartial observer, but rather, within the realm of qualitative research, the researcher is encouraged to acknowledge his or her own subjectivity, worldview, assumptions and preconceptions in order to ensure the integrity of the research. In qualitative inquiry, the researcher is the principal instrument for data collection and interpretation, therefore reflexivity becomes an important and essential aspect of the research process (Brantlinger, Jimenez, Klingner, Pugach & Richardson, 2005; Hatch, 2002; Watt, 2007).

Researchers working within interpretivist and qualitative frameworks are encouraged to make explicit their own positions within the research. As a chronically ill adult learner and researcher, reflexivity was a particularly important aspect to my research. Reflecting on my own subjective thoughts, feelings and worldviews assisted me in being more aware of the influence of my own perceptions and interpretations of the data and the research process itself. During the research process I kept a journal where I regularly recorded my experiences and thoughts as I worked through the literature, the data and ultimately the final write up of the research. As my study used a narrative approach, my use of journaling in order to maintain reflexivity, fit within the assumptions and understandings underlying this study. A more in-depth discussion of the narrative approach follows.

3.4 Approach

3.4.1 Narrative Inquiry

Humans make sense of their world through stories. Humans construct these narratives in order to interpret and explain, for themselves and others, the world as they see it (Bell, 2003; Clandinin & Huber, 2010; Connelly & Clandinin, 1990; Hart, 2002; Sikes & Gale, 2006). Their narrative accounts, in turn, become data (Sikes & Gale, 2006). Narratives become an organising principal for human experiences on an individual, communal and societal level (Bell, 2003). These narratives translated into the research process itself as I constructed and shared my own narratives and interpretations in order to understand what I was reading, seeing, hearing and participating in. Even the write up of this research was a narrative which I had, in collaboration with others, created. This brought with it an enormous sense of responsibility, for me as a researcher, to ensure an honest reflection of the stories shared by the participants that was not dominated by my own voice, but still provided room for my own narrative and positioning.

Narrative inquiry is one approach used in qualitative research to understand the subjective worlds of people. The view that research is in itself a narrative, as well as a process of data generation, has garnered support in the social sciences due to the growing discontent with meta narratives and scientific grand „truths“ (Sikes & Gale, 2006). Critics of narrative research, who proclaim narrative as an overly subjective, „weak“ source of data which is ultimately flawed with questionable validity, have been met with the argument that “all approaches to, and understandings of, research are „made up“ social constructions” (Sikes & Gale, 2006, Using narrative to inquire, para. 2). Therefore, narratives can and do offer an important way to build knowledge and understanding about the world around us.

Narrative inquiry is a fitting approach for understanding the challenges and experiences faced by mature adult learners with „hidden“ disabilities in higher education. A narrative approach, within this study, provided the students the opportunity to tell their own stories and it provided me with a glimpse of their inner worlds, perceptions and the meanings they ascribe to their experiences in life (Sikes & Gale, 2006). Narratives are not created in isolation; rather, they are mediated by our social and cultural backgrounds, which in turn provide us the opportunity to examine the social and cultural fabric within which people’s stories play out

and how these aspects contribute to the meanings people ascribe to their experiences and what they understand to be „true“ and „real“. The story of an individual might also and simultaneously be the story of a community, a culture and a society, with all the complexities that this involves. A story thus always resonates with other stories. What comes with this, is the need to understand that narratives are a reflection of someone’s worldview; but whose worldview? It needs to be considered, when listening to or reading a narrative, whose view this narrative really represents, what dominant discourses, conditions and circumstances have influenced and moulded its telling. In order to facilitate a more holistic understanding of the given narrative, this reflexive stance is essential (Hart, 2002; Sikes & Gale, 2006).

Narrative inquiry challenges researchers to be open to ambiguity and to search for and be comfortable with multiple meanings, but, due to our own social sense of „reality“, we as researchers evaluate narratives for „truthfulness“ in terms of how well the story fits within and represents the social and cultural structures from which the narratives emerge. Researchers “look at narratives in terms of their cultural credibility” (Sikes & Gale, 2006, Experience-near, para. 1). As was noted earlier, context influences narratives, how they are told, when they are told and how much of the story will be told (Clandinin & Huber, 2010; Connelly & Clandinin, 1990; Hart, 2002; Sikes & Gale, 2006). Sikes and Gale (2006) explore this further:

In social life generally we constantly story our lives in different ways, linking different events, experiences and perceptions, leaving different gaps and using different words and metaphors, in order to fit specific contexts, purposes and audiences. Not only might our stories alter depending on the context and what we judge to be appropriate, politic or useful (to us or the hearer), they differ from other people’s stories as a result of the unique combination of experiences we have had and the knowledge we have amassed as we go through life. This also means that as we gain more knowledge and develop new perspectives, forget or remember different details, our own interpretations and hence our stories may also change. (Narrative accounts of lives, para. 2-3)

These shifts, changes and adaptations in the narratives we create and tell result in a plurality of selves and actualities (Sikes & Gale, 2006). This fits with the multiple-selves and I-positions postulated by the Dialogical Self Theory, which I discussed in chapter two.

It is essential that the narrative researcher is conscious of the multiple selves and realities that play out in narratives, as well as the varying level of skill that narrators have in telling a story. Lack of language skills and storytelling ability may hamper the narrative and thus the researcher's ability to understand the person's story and its message and subsequently to draw meaning from it (Sikes & Gale, 2006). Additionally, there is an ethical obligation and a need for mindfulness when a researcher tries to „bridge the gap“ between the story the narrator is sharing and the researcher's interpretation and analytical write-up of that narrative for the purposes of research. Geertz (1988 as cited in Josselson, 2007) summed this up.

The gap between engaging others where they are and representing them where they aren't, always immense but not much noticed, has suddenly become extremely visible. What once had seemed only technically difficult, getting "their" lives into "our" works, has turned, morally, politically, even epistemologically delicate. (p. 537)

There are numerous ways to analyse narratives such as the analysis of structural qualities and plot sequences, emergent narrative themes and storylines. Themes, which were of interest to me in my study, primarily acted as an organising principle of related content that in turn revealed concepts or messages that the narrator or narrative was trying to explicate. Thematic analysis is a fitting approach to analysing themes within the narrative context (Sikes & Gale, 2006). The intricacies and methods involved in thematic analysis are discussed in greater detail later on in this chapter.

As there are numerous ways to analyse narratives, there are also a number of ways or methods for data collection within narrative inquiry, one of which, is the narrative interview (Sikes & Gale, 2006). As this was one of my chosen data collection methods, this is examined more closely under „Data Collection Methods“.

3.4.2 Illness Narratives

It would be prudent to add that there is a field of research dedicated to „Illness Narratives“. Deriving from a biomedical background, the study of illness narratives developed as way to better understand patients' experiences of illness. Illness narratives provide doctors with valuable insight into how those living with illness make meaning of their condition and how they adapt to and incorporate the experience of illness into their lives. Illness narratives

position patients' experiences as an important source of knowledge in understanding the nature of illness and the effects thereof (Bury, 2001; Levy, 2005; Williams, 1984). Illness narratives have medical undertones and tend to position people as patients. The aims and nature of this study are inherently different to those encompassed in illness narratives and thus, I adopted thematic analysis as a way to analyse the narratives shared by the participants. A discussion on thematic analysis features further on in this chapter.

3.5 Sampling

For the purposes of my study I selected, through the use of a snowball sampling technique, four chronically ill mature adult learners with autoimmune or chronic illnesses with similar symptomology, enrolled at any South African university or higher education institution. In this sample I also included myself as a participant; in turn creating a sum total of five participants for this study.

3.5.1 Snowball Sampling

Due to the hidden and sensitive nature of the topic, finding participants was not an easy task. Therefore, a snowball sampling technique, particularly useful in studying hidden populations, proved helpful (Atkinson & Flint, 2001). As I also fit the characteristics of the research participants, this went a long way toward breaking down many of the barriers that other researchers might have had to face in finding additional participants. I started with my own contacts and networks, and through word of mouth found the next participant, who in turn, identified and led me to another and so on, which created a cumulative social web. Snowball sampling in many ways appears less formal than more traditional methods and in turn puts people, particularly those considered to be members of vulnerable „hidden“ populations, at ease. Through this sampling method, participants are „recruited“ by friends or acquaintances who have become participants themselves. This helps develop the potential participant's trust in the researcher, as the researcher is in a sense being „vouched for“ by the „friend“ participant, but of course this is dependent on the relationship between the „friend“ participant and the potential participant. Therefore, snowball sampling relies on the quality of relationships and social knowledge. Additionally, it requires the researcher to become an „insider“, someone who can be trusted; therefore, the ability of the researcher to establish meaningful relationships with potential participants is crucial. In essence, it is the participant

that will lead the researcher to the next participant. If issues with the participant arise, this will ultimately impact on the chain of referral (Atkinson & Flint, 2001; Noy, 2008).

Drawbacks involved in this method are problems with sampling bias and accurate representativeness of the population, which ultimately affects the sample's validity. The participants selected are subjectively chosen by the first participants identified and selected by the researcher. This means that the participants who are included in the network are part of a particular social network and those that are not within this network will be missed, resulting in a sample that is "biased towards the inclusion of individuals with inter-relationships" (Atkinson & Flint, 2001, p.4). When the initial participants identify other potential participants, they will do so by choosing those they perceive to fit the criteria best and who feature most prominently in their minds. This will privilege particular members of a population over others. This results in the researcher tapping into only one social system without being able to tap into those who are isolated, who could provide unique information to the research project in question. Snowball sampling depends on the coherence of social networks within the population under study. The social networks of hidden populations, such as adult learners with „hidden“ disabilities, may not function as coherently as other population groups. As Atkinson and Flint (2001) explain "some groups may themselves consist of highly atomised and isolated individuals whose social networks are relatively impaired" (p. 3). In order to try and address this issue, I decided to also look for participants outside of my own social network on the UKZN Notice System website where I posted a notice requesting participants. This of course had its own limitations such as only accessing those who would go online to view these notices, but it did provide an additional source of potential participants outside of my own network. I also placed notices on the physical notice boards found on the UKZN campus grounds. This, unfortunately, did not provide me with enough participants; so other methods had to be employed.

Generally, a researcher will require previous knowledge of „insiders“ who can lead them to other participants. This has often been overcome by accessing those in authority who can lead the researcher and provide access to the population they want to study, but this is in itself inherently problematic due to „gate-keeper“ bias and power dynamics that can influence the outcome of the data gathered from the participants (Atkinson & Flint, 2001). Being an „insider“ myself, I was able to overcome some of these issues, although I still needed to be aware of my own power as a researcher and the impact thereof. „Gate-keeper“ bias did

become an issue of concern when I had to branch out by enlisting the help of a Psychologists' group in approaching possible participants that were known to them. This was conducted with sensitivity and respect for their clients' privacy and needs at the forefront. Their clients remained unknown to me until they reached out and contacted me directly, expressing their interest to participate, thus, providing them agency and control over their involvement.

The Psychologists' group proved to be the most helpful social network that I accessed, as they were able to approach potential participants that I would otherwise not have been able to reach. Additionally, the therapeutic nature of the relationship between the psychologists and their respective clients provided the participants additional support.

In closing, Atkinson and Flint (2001) assert that "the real promise of snowball sampling lies in its ability to uncover aspects of social experience often hidden from both the researcher's and lay person's view of social life" (p. 4). Thus, snowball sampling allows us to tap into and have access to the lives and experiences of those who previously have been overlooked due to being hidden or difficult to find, consequently growing and enriching researchers' and lay persons' understanding of the population in question by providing a more multi-voiced and comprehensive view.

3.6 Data Collection Method

The data collection method I chose for this study needed to compliment the basic assumptions and principles encompassed by the paradigm, approach and research style underpinning the research. For this reason, I chose narrative interviewing as a data collection method, as it provided a platform which encouraged storytelling and allowed for and privileged the life-worlds and narratives of those who participated.

3.6.1 Narrative Interview

Central to narrative research is interviewing (Bell, 2003). In research, a person's story or narrative is woven together "from threads of interviews, observations and documents" (Riessman & Speedy, 2007, p. 429). Interviews allow participants the opportunity to express themselves, to share their stories (Merriam, 2009), but what must be kept in mind is that, although interviews are seen as a method to elicit an individual's view, the narratives from

these interviews are co-constructed between interviewer and interviewee (Beuthin, 2014; Elliott, 2005; Riessman & Speedy, 2007). Traditionally, in narrative interviews, the participant is called the respondent or narrator and is often referred to as the interviewee, whereas in my study I refer to those who participated as participants. This term, I feel, reflects a sense of an empowered individual who is actively involved in the construction and sharing of their worldviews through storytelling. They are participating, and this elevates them from a „passive“ respondent to an actively engaged individual who is integral in the formulation and expression of data. Throughout this particular part of the discussion, I have used the above terms interchangeably.

Narrative interviews developed as a critical response to the restrictive question-answer format typical of traditional interviews. Traditional interviews restrict and impose upon the interviewee or participant certain structures that may impede and limit the data elicited from the interview process in three significant ways, namely, the themes and topics around which the interview is based, the language used in the interview and the ordering of the questions are all determined by the interviewer (Bauer, 1996; Jovchelovitch & Bauer, 2000). In turn, the data gathered from this process “reveals more about the interviewer’s own relevance structures than about the issues under investigating [sic]. One could say: who asks the questions controls the situation” (Bauer, 1996, p. 2).

Thus, in order to facilitate storytelling that provided a more „accurate“ reflection of the participants’ perspectives and worldviews, I tried to position myself as a „listener“ to encourage the participants’ storytelling (Jovchelovitch & Bauer, 2000) and made a “conceptual shift away from the idea that interviewees have answers to [my] questions and toward the idea that interviewees are narrators with stories to tell and voices of their own” (Chase, 2005, p. 660). Following narrative interview guidelines to encourage storytelling led to a more authentic narrative that was not dominated by my researcher voice. Narrative interviewing emphasises that the researcher’s influence on and restructuring of the interview process needs to be minimised. In order to create a setting that is conducive to narratives, the typical question-answer schema is replaced by a narrative schema that encourages storytelling by the participants, using their own words, and ensures that the follow-up questions develop from the participants’ narratives, thus favouring what is relevant to the participant rather than to the researcher (Bauer, 1996; Jovchelovitch & Bauer, 2000).

Narrative interviews emphasise that language is not neutral and is a reflection of a person's worldview; thus it is essential that the language used in the interview is not prescribed by the interviewer, but rather guided by the participant. Although it is emphasised that the interviewer must not impose their own structures on the interview, this does not mean that the interview and subsequent storytelling is without structure. Storytelling, "as an elementary form of communication of human experiences" (Bauer, 1996, p. 3), is a self-generating schema that follows certain rules that guide, encourage and facilitate story production. It has three main characteristics. Firstly, „Detailed Texture“ is provided by the narrator through descriptive information in order to facilitate transitions from one event to the next in a way that lends credibility to the story and ultimately makes sense. Secondly, „Relevance Fixation“ pertains to aspects of the event that are relevant to the narrator and thus are shared within their storytelling, providing us with a glimpse of their worldview and relevance structures. Lastly, „Closing of the Gestalt“ is the principle that all events that are mentioned within the storytelling must come to an end; all stories have a beginning, a middle and an end, so once the story has ended there is some form of closure, whether the event has ended in real life or not; this process of closure encourages a story to unfold (Bauer, 1996; Jovchelovitch & Bauer, 2000). There are certain guidelines that can help initiate the storytelling schema and maintain the storytelling through the self-generating schema.

3.6.1.1 Narrative Interview Technique

In essence there are four phases in a narrative interview and an initial pre-interview stage. The narrative interview technique requires researchers to prepare for the interview by researching the area of interest and formulating an initial central topic that "is designed to trigger a self-sustainable narration" (Jovchelovitch & Bauer, 2000, p. 5). The researchers then create a list of „exmanent“ questions, which are research questions formulated in the researcher's own language that reflect his or her interests. The researcher then translates and formulates these „exmanent“ questions, using the narrator's own language, into „immanent“ ones which reflect the issues revealed by the narrator (Bauer, 1996; Jovchelovitch & Bauer, 2000).

Exmanent issues and immanent issues may not at all, partially or totally overlap...[i]n the course of the interview the exmanent questions will focus the attention of the interviewer; he or she will note overlapping issues as they come up, and make notes

of the language used for further questions at the appropriate time. (Bauer, 1996, pp. 5-6)

Once the initial investigation, the pre-interview, is complete then the researcher can continue with the interview of the participant.

The first of the four phases in a narrative interview is called „Initiation“, where the researcher explains to the participant the general context of the research and how the interview will proceed, and gains the participant’s permission to record the interview on tape or digitally (video and audio). Recording of the interview is regarded as an essential tool to the narrative interview, as it allows for a more natural interaction between the researcher and participant and assists in analysis as a reliable verbatim record of the narratives produced from the interview. I used two recording devices; namely, a voice recorder and a video recorder which the participants gave me permission to use in order to record the interviews. The video recorder functioned as a back up in case the voice recorder failed (and vice versa). I focused the video recorder on the participant. This assisted me in terms of capturing non-verbal language (which added an additional layer to the participants’ story telling for the purposes of analysis) that could not be captured through voice recording. Both recording devices were small and unobtrusive and did not seem to hinder or impede the participants’ story telling. Additionally, I journaled my observations about the interview, the participant and what transpired, after the interviews had taken place. This provided me with additional data that was not necessarily recorded in the interview process itself such as my first impressions of the participants.

The initial central topic is introduced in order to encourage the participant’s storytelling. A number of guidelines around the initial central topic will have been proposed in order to sustain storytelling from the participant. These guidelines suggest that the central topic needs to be broad, without references to particular dates, names or times to allow for unhindered storytelling and the central topic needs to be relatable or experiential to the participant, as well as having social, personal and communal import (Bauer, 1996; Jovchelovitch & Bauer, 2000). Elliott (2005), though, points out that it may be very difficult for people to sustain storytelling without a time frame of some kind. For the interviews conducted in my study, I found that providing a point in time was useful to prompt storytelling. Typically, I would ask the participant to reflect on life before they became ill and follow that by asking what

happened next. This proved to be very successful in prompting and sustaining a rich narrative.

The second phase, „Main Narration“, focuses on uninterrupted storytelling by the participant, where it is essential that the interviewer does not interrupt or ask questions, but rather listens attentively and provides non-verbal encouragement and support whilst developing in their mind the immanent questions that will follow in the next phase (Bauer, 1996; Jovchelovitch & Bauer, 2000). When the participant’s story comes to a natural end, the interviewer may probe slightly and ask if that is all the participant would like to say. At this point the interview moves onto the third phase, called the „Questioning phase“, where the interviewer can now ask the immanent questions that have developed from the initial exmanent questions throughout the storytelling phase in order to “complete the gaps in the story” (Bauer, 1996, p. 7). Three guidelines pertain to this phase, which suggests that the interviewer only ask immanent questions which apply to events, using the participant’s own language, and not ask why-questions that will prompt opinions or attitudes. Lastly, the interviewer needs to ensure that contradictions in the participant’s story do not become an issue of scrutiny. Fundamentally, the “question phase is meant to elicit new and additional material beyond the self-generating schema of the story” (Bauer, 1996, p. 8).

Phase four, „Small Talk“, is conducted in a far less formal manner when the recording devices are switched off (this action does not mean that conversations between the interviewer and participant are now „off the record“ - this is explained to the participant) and a more natural conversation ensues between the interviewer and participant. This phase can be particularly enlightening and provide information that otherwise may not have been revealed in the formal phases of the interview. This additional information can be exceptionally useful in providing context and assisting in the analysis and interpretation of the narratives (Bauer, 1996; Jovchelovitch & Bauer, 2000).

3.6.1.2 Length of Narrative Interviews and Repeats of Interviews

Various authors suggest between two to three hours as an appropriate length for a narrative interview (Elliott, 2005; Seidman, 2006). This provides „enough time“ for in-depth storytelling without becoming too cumbersome. It also provides a time frame that lends structure to the interview process and instils a sense of how much detail the participant is

expected to share, considering that time frame. Elliott (2005) explains that “[i]f the quantity of material to be covered in an interview is judged to need more than two hours then the most practical solution is to conduct a second and even third interview” (p. 32). Seidman (2006) suggests a series of three interviews of 90 minutes each in order to gather sufficient information, but considering the health of my participants and the intensity of the process, I decided that one session of two hours would be best, which ensured that both I and the participants did not grow too fatigued.

The two hours proved to be a good time frame in which to conduct my interviews. The time was sufficient for the participants to share with me complex, multifaceted and richly detailed narratives. A longer interview would not have served the participant or me as, typically, towards the end of each interview we would both tire and become non-productive. I was able to incorporate all four stages within the interview, but I deviated from „protocol“ from time to time in order to accommodate the participants“ and my own needs (such as bathroom breaks, cigarette breaks, checking on comfort levels, closing curtains and so on). Although there were these types of „disruptions“ this did not seem to hinder the storytelling process. In many ways it created a more relaxed environment where „just being human“ engendered a sense of normalcy and reciprocity. All of the participants were interviewed face to face in this manner, except one with whom I conducted an email interview due to geographical distance and for the convenience of the participant.

3.6.1.3 Limitations and Strengths of the Narrative Interview

Two primary issues with the narrative review are: “(a) the uncontrollable expectations of the informants, which raise doubts about the strong claim of non-directivity of the NI, and (b) the often unrealistic role and rule of its procedures” (Jovchelovitch & Bauer, 2000, p. 6). In a narrative interview, interviewers need to play the role of a person who knows very little of the subject at hand and who has no particular vested interests, but this is unrealistic and perhaps somewhat dishonest. The narrative interview prescribes that the interviewer needs to research the area of interest beforehand and come to the interview „prepared“. If the interviewer is to play this ostensibly ignorant role, it could possibly relay a sense of dishonesty to the interviewee. This can be damaging where trust is paramount to facilitating an authentic narrative. The interviewees, regardless of any efforts of the interviewer presenting themselves as naïve, have certain expectations that the interviewer does have some

kind of previous knowledge of the area being researched. This has an additional effect where the interviewee, in the telling of the story, will make certain assumptions about how much the interviewer knows and therefore may leave out parts of the story they feel the interviewer is familiar with, which may not necessarily be the case. This runs the risk of the interviewee leaving out critical parts of information that could have a substantial impact on the understanding and interpretation of the narrative shared. This narrative is influenced and shaped by the relationship between the interviewer and interviewee in terms of trust and certain assumptions and expectations held by both parties (Bauer, 1996; Jovchelovitch & Bauer, 2000). In essence, the narrative is co-constructed and mediated by a number of dynamic factors (Bauer, 1996; Beuthin, 2014; Elliott, 2005; Jovchelovitch & Bauer, 2000; Riessman & Speedy, 2007).

Any conversation is guided by expectations of expectations. Even in cases where the interviewer abstains from framing questions and answers, the active informant will tell her story to please or frustrate the interviewer, or to use the interviewer for purposes beyond the interviewer's control. In all cases, the informant's relevance structures may remain hidden. The narration reflects the interpretation of the interview situation. Strategic storytelling cannot be ruled out. (Jovchelovitch & Bauer, 2000, p. 7)

Additional limitations identified are that the rules pertaining to the initiation of the interview are difficult to standardise and depend highly on the social skills of the interviewer. The absence of these essential social skills can be a source of stress for the interviewer. Furthermore, it can result in a lack of consistency across a number of interviews where different interviewers with varying social skills have been used (Bauer, 1996; Jovchelovitch & Bauer, 2000).

In my study I conducted an individual, in-depth, narrative interview with each of the participants to garner insight into their experiences. All the participants, except for one, were interviewed face to face. I adopted the same narrative interviewing style in my email interview with the one participant, but there were some subtle differences in terms of advantages and disadvantages in using this medium. Primarily, there were difficulties in facilitating storytelling without falling back on a more restrictive question-answer schema in order to gather sufficient data. Additionally, I could not pick up on facial or non-verbal cues,

which could potentially have added to the narrative. However, as identified by literature on email interviewing, there are certain benefits inherent in this medium (Bowker & Tuffin, 2004; Cook, 2012; Meho, 2006), for example, the participant has time after a question to craft a “reflexive response” (Cook, 2012, p. 1335). Additionally, due to the participant being ill, email interviewing allowed her the participation in the interview from the comfort of her home and in her own time, affording her a sense of control over the interview (Bowker & Tuffin, 2004; Meho, 2006).

In general, the open-ended questions asked in these interviews developed from the narratives themselves shared in the interview. Although for each of my interviews my exmanent questions were mostly the same, the immanent questions that arose from the narratives shared with me differed slightly, as each person’s story had its own unique characteristics and in turn produced immanent issues that reflected that uniqueness. I could not play the role of the „ignorant“ researcher, as the participants were aware of my own chronic illness, but I came to the interview and presented myself as someone who did not know their unique story. I believe that the participants’ awareness of my chronic illness aided in the development of a relationship based on a deeper understanding of each other that perhaps may not have been achieved by someone who had never experienced illness of this nature. Being the only interviewer in this study also ensured a certain level of consistency in terms of social skills and interviewing techniques.

3.7 Data Analysis

Data analysis in qualitative research, in itself, is a process of meaning making (Merriam, 2009). In narrative research, it is the task of the researcher to retell or re-story the narratives that the participants have shared (Guest et al., 2012). Suter (2012) explains that “the challenge for the researcher is to define the elements of the person’s stories (the raw data), identify themes, uncover important sequences, and retell the story in ways that provide insight (the meaning of the story)” (p. 369). I used thematic analysis to identify implicit and explicit ideas and subsequent patterns from within the data. Themes and coding were applied in order for me to analyse the narratives (Braun & Clarke, 2006; Gibbs, 2007; Marks & Yardley, 2004; Riessman, 2008; Vaismoradi, Turunen & Bondas, 2013).

3.7.1. Thematic Analysis

Thematic analysis is a method used by researchers to identify, collate and analyse themes and patterns from within the data (Braun & Clarke, 2006; Guest et al., 2012; Marks & Yardley, 2004; Riessman, 2008; Vaismoradi et al., 2013). Thematic analysis is one of many approaches that can be used when analysing narratives. Due to its relative „straightforwardness“ and flexibility, it is a fairly common method (Braun & Clarke, 2006; Riessman, 2008). Despite this, very little has been written about the specific methods and applications of thematic analysis, resulting in “a poorly demarcated and rarely acknowledged, yet widely used qualitative analytic method” (Braun & Clarke, 2006, p.77). The above mentioned researchers have endeavoured to clarify this method, its applications and its subsequent evaluation, which I reflect in the following discussion. Essentially, thematic analysis looks at „what“ is being said: the content located in the data (Riessman, 2008). Thematic analysis can be applied to data elicited from interviews (Riessman, 2008).

3.7.1.1 Themes

Themes or coding categories are patterns that emerge from the data. Patterns may emerge through manifest or latent content. Manifest content tends to be observable, surface level data, whereas latent content tends to be less obvious and rather implied, which requires a level of interpretation on the part of the researcher. If one is coding for a theme regarding prejudice, an example of manifest content would be if the participant explicitly mentions the word „prejudice“, whereas, if the participant talks about „fear of revealing their illness“, this could be construed as latent content of the same theme. Additionally, themes can develop inductively or deductively: themes may emerge from the raw data themselves (inductively) or may develop from pre-established theoretical concepts that the researcher applies to the data (deductively) (Braun & Clarke, 2006; Gibbs, 2007; Marks & Yardley, 2004); or from both. Existing theories can help guide the questions one asks in research and assist in the analysis and meaning making of the respective answers. Inductive themes are particularly useful in new areas of research. However, as Marks and Yardley (2004) note, “no theme can be entirely inductive or data driven, since the researcher’s knowledge and preconceptions will inevitably influence the identification of themes” (p. 58). Researchers, code data in order to categorise, order, compare and make sense of highly complex, detailed information. This

coding process is an essential aspect of theme development (Braun & Clarke, 2006; Gibbs, 2007; Marks & Yardley, 2004).

3.7.1.2 Codes

Codes are a form of labelling that is assigned to different portions of data in order to categorise and sort data into themes. These codes are driven by the questions one aims to answer and the basic underlying assumptions of the research at hand. From the data, the researcher needs to draw out aspects that are relevant to the research questions, but also be open to new or conflicting data that can add to or refute the developing or pre-existing theory (Gibbs, 2007; Marks & Yardley, 2004).

In order to answer research questions, researchers code and subsequently create a coding frame that will serve as a framework in order to understand and interpret the data. At its most basic level, coding involves the identification of patterns and the labelling of the said patterns with codes relevant to the research. This coding allows for the organisation of data into meaningful categories that enable researchers to make sense of and have deeper insight into the phenomenon of interest (Gibbs, 2007; Marks & Yardley, 2004).

The researcher chooses which aspects of the data will be assigned codes. Decisions are made on whether each phrase, word or sentence will be used as a coding unit or if larger units such as entire interviews will be coded. The researcher also makes decisions about whether a coding unit can only be coded into one category or multiple categories. This mostly depends on whether the researcher will be using quantitative analysis, where exclusive categories are required, or qualitative analysis, where some overlap is acceptable. A large, broad coding unit normally lends itself to multiple categorisations and thus it is not ideal for quantitative statistical analysis where comparisons of independent categories are a core feature (Marks & Yardley, 2004).

The labels assigned to codes need to be clearly defined. Marks and Yardley (2004) explain that “[a] code should have a label, an operationalization of what the theme concerns and an example of a chunk of text that should be coded as fitting into this category” (p. 60). Once labels have been assigned to the codes, coding can take place. Depending on the kind of thematic approach adopted, coding can occur in a hierarchal fashion where the researcher

starts with pre-defined theoretical, over-arching higher order categories, from which smaller, related subcategories develop. These categories guide the coding. Categories may also develop inductively from the data themselves, where a bottom-top effect occurs, developing from smaller subcategories and building to larger, broad categories. This type of coding occurs at a textual level which is later combined to create meaningful, overarching concepts. Two processes are used in this, namely, splicing and linking.

Splicing...is the fusing together of a set of codes under an overarching category. It involves increasingly focusing the categorisation activities in the knowledge that it will be impossible to incorporate all codes into the final analysis. This process of fusion involves the researcher thinking through what codes can be grouped together into more powerful codes. (Marks & Yardley, 2004, pp. 61-62)

Linking involves themes “allowing for higher order abstraction and interpretation” (Marks & Yardley, 2004, p. 62). These two processes are driven by theoretical concepts or from the raw data.

3.7.1.3 Coding to Analysis

Once all the data have been coded, analysis can commence. A coding manual is created containing a detailed description of all the codes that have been developed. This coding manual serves as a point of reference with regard to testing the reliability of the codes. If the codes are clearly defined and explicit, the researcher should be able to use the codes consistently and consequently other researchers should be able to apply those codes with the same result. Although reliability testing such as inter-rater reliability (where two independent coders assign codes to the same data and consistency between the two is examined) is usually practiced in quantitative analysis, it still is a useful process to engage in for qualitative analysis, as it cements and makes clear the parameters of the coding (Marks & Yardley, 2004). Providing a clear rationale regarding coding decisions will help strengthen and validate the coding process. An explicit, detailed coding frame allows for scrutiny, examination and discussion, which strengthens the coding frame as a whole and consequently supports the resultant analysis (Braun & Clarke, 2006; Marks & Yardley, 2004). This ensures that the coding frame used in the research can be used by others, as it is “transparent, coherent and understandable, as opposed to an idiosyncratic, opaque system of interpretation

devised by a single researcher” (Marks & Yardley, 2004, p. 63). Vaismoradi, Turunen and Bondas (2013) explain that, due to the nature of this analysis, credibility and scientific rigour associated with quantitative methods cannot be used in a qualitative research context. Within qualitative studies, validity and rigour are ensured through the use of qualitative measures, namely; dependability, credibility, transfereability and confirmability.

The coding process reveals reoccurring themes within the data. Frequent and infrequent themes emerge, which the researcher then compares to the relevant literature in order to establish a meaningful story. The frequency of a theme does not denote its importance. A rare theme may have substantial importance to the research at hand and thus it is up to the researcher’s discretion to make these distinctions and analyse accordingly (Braun & Clarke, 2006; Marks & Yardley, 2004; Vaismoradi et al., 2013). Marks and Yardley (2004) add that “[n]ew insights can often be provoked by attempting to understand what appear to be anomalies” (p. 64). The researcher needs to understand, decipher and identify links and make abstractions from the texts; these processes constitute an important analytical tool in thematic analysis. In essence, the researcher’s mind is the primary tool in research (Braun & Clarke, 2006; Marks & Yardley, 2004; Vaismoradi et al., 2013).

3.7.1.4 The Process of Thematic Analysis

Six phases, identified by Braun and Clarke (2006, p. 87), provide a useful guiding framework for the application of thematic analysis:

| Phase | Description of the process |
|--|--|
| 1. Familiarizing yourself with your data: | Transcribing data (if necessary, reading and re-reading the data, noting down initial ideas) |
| 2. Generating initial codes: | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. |
| 3. Searching for themes: | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. Reviewing themes: | Checking if the themes work in relation to the coded to extracts (Level1) and the entire data set (Level 2), generating a thematic „map“ of the analysis. |
| 5. Defining and naming themes: | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. |
| 6. Producing the report: | The final opportunity of analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis |

Table 3.1: *Phases of Thematic Analysis*

Thematic analysis can be described as a process. This process is not a rigid rule-based, step by step progression, but rather a flexible, recursive activity that requires the researcher to immerse themselves within the data (Braun & Clarke, 2006; Vaismoradi et al., 2013). Braun and Clarke (2006) explain that “[i]mmersion usually involves „repeated reading“ of the data, and reading the data in an *active* way – searching for meanings, patterns and so on” (p. 87). Making notes and jotting down ideas about possible codes during this reading phase will assist the researcher once the formal coding begins. The generating of codes is, in essence, the first level of analysis as data is arranged into meaningful categories requiring evaluation and interpretation of the data by the researcher (Braun & Clarke, 2006; Gibbs, 2007; Vaismoradi et al., 2013). On a practical level, using highlighters or brightly coloured pens is helpful when trying to identify codes and subsequent patterns, as it will assist in matching similar data extracts through the use of colour and will facilitate categorisation (Braun & Clarke, 2006; Gibbs, 2007).

As mentioned above, Marks and Yardley (2004) assert that coding will be influenced by whether the themes are „data driven“ or „theory driven“, which will either draw themes from the data themselves or data are coded according to specific theories or questions that the researcher has brought to the research itself (Braun & Clarke, 2006; Gibbs, 2007). Data sets can and do have incongruities, but this does not mean that one needs to “smooth out or ignore

the tensions and inconsistencies within and across data items. It is important to retain accounts that depart from the dominant story” (Braun & Clarke, 2006, p. 89). These peculiarities or unexpected data items can provide richness, depth and additional information that will provide new insight into your field of study (Braun & Clarke, 2006; Marks & Yardley, 2004; Vaismoradi et al., 2013).

After the initial coding and collation has been completed, analysis moves onto a broader level, where those collated codes are organised into probable, main and sub-themes. Once all data has been organised under plausible themes, the themes are reanalysed in order to refine and cement the themes. This refinement process requires two levels of review: At the first level, the data extracts are reassessed to check for coherency and on the second level; the entire data set is reassessed in terms of the validity of the themes in connection to the data set. Through this refinement process, themes are named and the core of each theme is identified and expressed (Braun & Clarke, 2006; Vaismoradi et al., 2013). Braun and Clarke (2006) add that “[a]s well as identifying the „story“ that each theme tells, it is important to consider how it fits into the broader overall „story“ that you are telling about your data, in relation to the research question or questions” (p. 92). The use of a thematic map can be particularly useful in providing a visual representation of how the identified themes interlink and fit into the broader picture. This process assists in re-evaluating the themes and establishing a coherent „story“ (Braun & Clarke, 2006; Vaismoradi et al., 2013).

After completing the above processes, one can proceed with the analysis and write up of the report. Here, the researcher needs to convey, compellingly, what the data is saying. The write up needs to include data extracts that support the themes identified. The analysis and subsequent write up need to provide “a concise, coherent, logical, non-repetitive and interesting account of the story the data tell[s]” (Braun & Clarke, 2006, p. 93). Braun and Clarke (2006) point out that it is essential that data extracts are not merely described, but analysed and put forth as evidence to support the researcher’s particular argument or theory. I adopted the above steps and processes in the analysis of the data revealed in this study.

3.7.1.5 My Process of Thematic Analysis

I immersed myself within the data through the process of transcribing the interviews and numerous readings and re-readings of the transcripts. I created a coding sheet (Appendix B)

with codes that I developed, inductively and deductively, from the data gathered from the transcripts and videos of the in-depth interviews. Words, phrases and sentences were assigned codes such as „identity roles“ (IR), „illness impact“ (III), „self“ (IPS) and „others“ (IPO). Some of these codes emerged inductively from the data themselves such as „illness impact“ (III) whilst other codes were developed and assigned deductively, drawing from the theoretical frameworks; for example the Dialogical Self Theory guided coding such as „identity roles“ (IR). The development of codes and coding was an iterative process.

I searched for patterns whereby I grouped codes, through inductive (data driven) and deductive (theory driven) processes, into larger themes, and after a process of refinement and review, named these themes; examples such as „identity and perceptions“, „support“ and „non-support“. I then analysed these themes in conjunction with the relevant theoretical frameworks to provide contextualisation and insight into the challenges and experiences of adult learners with „hidden“ disabilities in higher education.

3.7.1.6 Thematic Analysis – A Critique

A major criticism of this type of analysis is the fragmentation of text which can result in loss of meaning and de-contextualisation. This may also result in the loss of the rich, in-depth meaning of the „whole“. Marks and Yardley (2004) argue that “the whole interview is not only greater than the sum of its parts, but by „immersion“ in the whole one gains understanding of the parts, rather than vice versa” (p. 66). Additionally, through the process of coding, the researcher interprets text to suit a particular purpose. Researchers may organise and code data according to their “sense of how it connects, rather than the inter-relationship of themes in the participant’s mind or lifeworld” (Marks & Yardley, 2004, p. 66). This is highly problematic, considering the aims and underpinnings of narrative analysis where the primary purpose is to highlight the participant’s process of meaning making, understandings and worldview. Data are interpreted and influenced by the researcher’s aims and the relevant theories underpinning the research (Braun & Clarke, 2006; Gibbs, 2007; Riessman, 2008). With this in mind, and knowledge of the potential pitfalls, a researcher who is cognisant of their own aims and motives can take steps to avoid myopically interpreting the data. Recognising and explicitly expressing one’s own positionality, assumptions, worldviews and bias are essential in analysing and interpreting data in a way that remains faithful to the narrator’s meaning and worldview (Braun & Clarke, 2006). As I engaged with and

subsequently analysed the data, I was mindful of these aspects and endeavoured to avoid the above mentioned pitfalls.

It is essential that the researcher does not reduce the data to trivial, de-contextualised fragments, but rather ensures that the themes' context, richness and depth are preserved and expounded upon. Riessman (2008) explains that using thematic analysis in a narrative context avoids this fragmentation, that there is focus on keeping the narrative whole and analysing it within that context: “[N]arrative scholars keep a story “intact” by theorizing from the case rather than from component themes (categories) across cases” (Riessman, 2008, p. 52). However, this cross-case analysis might be a subsequent step in meaning-making.

3.8 Towards a Valid and Reliable Study

In the context of qualitative research, the use of validity and reliability is associated with a more positivist approach and does not fit with the assumptions and philosophies underpinning qualitative studies. Essentially, these constructs cannot sufficiently measure what they propose to measure when dealing with humans and human nature. Thus, different measures that can provide overall quality of the research at hand are required. A notable author, Guba (1981 cited in Shenton, 2004), proposes four criteria that will ensure quality and provide similar modes of enquiry that meet criteria associated with reliability and validity. These criteria are credibility, transferability, dependability and confirmability. Together, these constitute and contribute towards the trustworthiness of research (Krefting, 1991; Merriam, 2009; Rule & John, 2011; Shenton, 2004). These criteria are discussed in further detail below.

3.8.1 Trustworthiness

In qualitative research, trustworthiness is the alternative to validity and reliability. Trustworthiness is an important concept, as it is a way that allows qualitative researchers to evaluate the worth of their research outside the parameters of quantitative measures and terms. With this in mind, there are a number of elements which ensure the trustworthiness of research such as transferability, credibility, dependability and confirmability (Krefting, 1991; Merriam, 2009; Rule & John, 2011; Shenton, 2004). A discussion of each follows.

3.8.1.1 Transferability

Transferability is the qualitative answer to external validity or generalisability. It refers to whether the findings of a study can be applied to other settings. In the context of positivist research, external validity ensures that the results of the research can be generalised to the broader populace. Due to the nature of qualitative research, generalising from a small, unique group (such as the group in this study, consisting of five English-speaking, middle class white, coloured and Indian women) to the larger population is next to impossible, but with this said, the results of the research can still be relatable (Krefting, 1991; Shenton, 2004). Other researchers, whose research is contextually similar, can apply the findings of the research to their own studies. As long as the researcher provides enough detailed data and context in order for other researchers to assess relevance to their own settings, this requirement can be met (Krefting, 1991; Shenton, 2004). The context and relevant factors are provided by the researcher because they are considered important to the researcher. Factors that are deemed unimportant or inconsequential are subsequently left out of the description, which may have a significant impact on another researcher's work. This could potentially jeopardise the trustworthiness of their study. However, even if all the context and detail have been supplied and are applied correctly, there may still be inconsistencies in the results, but this does not necessarily indicate untrustworthiness. Shenton (2004) explains that "[i]t may be that they simply reflect multiple realities, and, if an appreciation can be gained of the *reasons* behind the variations this understanding may prove as useful to the reader as the results actually reported" (p. 71). Due to the rich, descriptive data derived and shared from the narrative inquiry utilised in my study, this criterion was met.

3.8.1.2 Credibility

Credibility is akin to internal validity. Credibility is related to how consistent the research results are with reality (Krefting, 1991; Shenton, 2004). It ensures that what the study intended to research was in fact researched. There are a number of provisions that a researcher can make when conducting their study to ensure credibility such as the use of well established research methods, subjecting the research to scrutiny and familiarisation with the culture of the participants. One of the ways that credibility was achieved in my study was through my immersion in the culture of the participants. As a chronically ill adult learner, I was automatically familiar with and immersed in this culture and this provided me a „fore-

knowledge“ of sorts. I also endeavoured to accurately represent the narratives shared with me. I therefore, on a regular basis, checked that my understandings and interpretations of what the participants had shared were correct. Throughout the interview process, I would rephrase and echo back aspects of what the participant had told me; this provided them the opportunity to agree with or correct my understanding of what they told me, ensuring that my interpretations were an authentic reflection of their stories. I ensured that I had frequent debriefing sessions with my supervisor who could point out flaws or provide new perspectives, as well as scrutinising my research as it unfolded (Krefting, 1991; Lietz, Langer & Furman, 2006; Shenton, 2004). Participants must come into the research process willingly. It needs to be emphasised that it is voluntary and that they can withdraw at any time. An unwilling participant may be dishonest and compromise the results of the study. The relationship between the researcher and the participant will also influence the honesty with which the participant will share their stories (Krefting, 1991; Shenton, 2004). I relied on my relationships with the participants to elicit honest responses from them. This was dependent on my ability to build strong, trusting relationships with them, which I felt was achieved through our shared difficulties of being ill.

Outside scrutiny of the research process by peers, academics and others, as well as scrutiny from within, in the form of „reflective commentary“, are additional measures used to ensure credibility (Krefting, 1991; Lietz et al., 2006; Shenton, 2004; Watt, 2007). I utilised these two methods by presenting my research to various audiences and kept a research journal which I regularly wrote in, in order to keep track of and reflect on my impressions of the research as a whole and on the thought processes behind the subsequent development of the themes.

These are but a few examples of ways to ensure credibility, therefore the above list is not exhaustive, but rather some of the techniques I employed for my study.

3.8.1.3 Dependability

Dependability is the qualitative response to reliability. Reliability, in positivist research, is based on the premise that if certain methods are utilised, a subsequent study can be conducted using the same techniques, the same participants within the same context, which would result in comparable findings. Be that as it may, the fluidity and constantly shifting contexts of phenomena under investigation require alternative methods to ensure dependability (Shenton,

2004). Dependability “focuses on methodological rigour and coherence of generating findings and case accounts which the research community can accept with confidence” (Rule & John, 2011, p. 107). Credibility and dependability are closely linked and “a demonstration of the former goes some distance in ensuring the latter” (Shenton, 2004, p. 71). Dependability may be achieved through a number of methods. This can be done by describing the research design and its implementation, reflecting on the process and providing detail of the data gathering, which I detailed in this chapter (Krefting, 1991; Lietz et al., 2006; Shenton, 2004; Watt, 2007).

3.8.1.4 Confirmability

Confirmability is the qualitative response to objectivity. Shenton (2004) asserts that “steps must be taken to help ensure as far as possible that the work’s findings are the result of the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher” (p. 72). With this in mind, it was important that I was aware of my influence on the study and my own bias and worldview (Krefting, 1991; Lietz et al., 2006; Rule & John, 2011; Shenton, 2004). My positionality, as a chronically ill researcher, could have influenced the choices I made, my interpretation of the results and the study as a whole. My disclosure and an on-going reflective commentary helped towards meeting the criteria of confirmability (Krefting, 1991; Rule & John, 2011; Shenton, 2004; Watt, 2007). I kept a diary of my own and recorded my experiences of being a researcher, a student and someone who is chronically ill. This helped me be more aware of my own thoughts and feelings as I moved through the research process. A detailed description of the methodology and how the constructs were developed in the write up of the research provides a way for others to scrutinise and follow the thought processes and decisions made by the researcher; in other words it needs to be auditable (Krefting, 1991; Lietz et al., 2006; Shenton, 2004; Watt, 2007). This detailed methodological description is provided both in the methodology chapter and in the analysis chapter contained within this dissertation.

3.9 Ethics

Ethics plays a role in the validity and reliability of the research (Merriam, 2009). Three important aspects that need to be taken into consideration are autonomy, non-maleficence and beneficence (Rule & John, 2011). These students shared their personal stories about living

with a „hidden“ disability. They and their stories needed to be treated with respect, dignity and value. The participants were informed of the exact nature and purposes of the study, how long their participation would be required and the exact nature of that participation. They were informed that they had the opportunity to withdraw from the study at any time.

Reflecting on the effects of living with chronic illness could have been potentially upsetting and stressful for the participant. Therefore, I arranged that the participants could access counselling, either from the University of KwaZulu Natal’s student counselling services at the Pietermaritzburg campus, or through the psychologists who I met the participants through. The participants’ privacy, anonymity and confidentiality are of the utmost importance, thus using pseudonyms and ensuring that the stories they provided me were protected went some way toward upholding these ethical principles. Arrangements were made to protect transcripts and other relevant data. Videos of the interviews were deleted.

My hopes were that through the process of sharing their stories, these people would leave the process having felt they had gained something; whether it was a new support system or the feeling they had contributed to helping others like themselves. This addressed the ethical principle of beneficence.

3.9.1 Ethical Considerations in Narrative Research

Ethical research requires certain criteria to be met which will ensure the protection of those who are involved in a study. Those who participate should do so only if it is of their own free will, their confidentiality and anonymity must be protected and ultimately, the research must not cause harm to those who participate (Josselson, 2007; Rule & John, 2011) .

Due to the rich detail provided in narrative research, anonymity can be an issue. Rich data often contains identifiers or a unique set of characteristics which may cause participants to be identifiable. There is a precarious balance as to which identifiers to change to ensure anonymity without losing the „person“ in the „story“ (Kaiser, 2009). In terms of this study I used pseudonyms but retained details such as their occupation and field of study as these aspects were integral to understanding the participant and their respective narratives. I excluded the participants’ locations and the names of the institutions where they were studying, to reduce the risk of the participants being identified.

Besides the general ethical principles of autonomy, confidentiality, non-maleficence and beneficence (Rule & John, 2011), narrative research requires researchers to examine the research relationship in greater detail due to the inherent nature of narrative inquiry. Narrative research, for the most part, is heavily reliant on the relationship between the researcher and the participant, and herein lies the potential for ethical dilemmas (Josselson, 2007).

[T]he narrative researcher is in a dual role - in an intimate relationship with the participant (normally initiated by the researcher) and in a professionally responsible role in the scholarly community. Interpersonal ethics demand responsibility to the dignity, privacy, and well-being of those who are studied, and these often conflict with the scholarly obligation to accuracy, authenticity, and interpretation. (Josselson, 2007, p. 538)

In the realm of narrative research, there are no hard and fast rules that a researcher can adhere to in order to satisfy the above mentioned ethical principles; instead, a researcher has to use their own judgement as they constantly weigh up their responsibilities in producing accurate and reliable research and protecting those who participate within that research. The researcher has an important moral responsibility when working with the narrations of other peoples' lives. These narrations are entrusted to the researcher and thus require respect, honour and due care. Josselson (2007) discusses a number of ethical requirements one usually undertakes in research and examines how, within a narrative relationship, they become increasingly complex. Firstly, Josselson (2007) argues that there is an explicit and implicit contract between the researcher and participant. The explicit contract, which states the role and nature of the research and the researcher-participant relationship, is typically uncomplicated, but due to the individualised and intimate nature of the relationship that is built between researcher and participant through narrative inquiry, an implicit contract comes into play. Narrative research and the level at which a participant will reveal their story, relies heavily on the quality and level of trust engendered by the researcher-participant relationship.

[T]he nature of the material disclosed is influenced not by the explicit contract but by the trust and rapport the researcher/interviewer is able to build with the participant. Thus, the participant is reading, not what has been made explicit, but rather the subtle interpersonal cues that reflect the researcher's capacity to be empathic,

nonjudgmental, concerned, tolerant, and emotionally responsive as well as her/his ability to contain affect-laden material. (Josselson, 2007, p. 539)

The more the participant trusts the researcher, the more they are likely to reveal, under the assumption that their story will be valued and treated with compassion. This reflects the implicit contract. Josselson (2007) explains this further: “What constitutes respect and compassion in the minds of this researcher/participant pair is the nature of the implicit contract between them” (p. 539). This implicit contract is difficult to define or make explicit as assumptions and expectations may differ. However, this contract is an essential aspect to the research relationship, as it will determine the strength and depth of the relationship, which ultimately impacts on the quality of data revealed by the participant (Josselson, 2007).

There are a number of other ethical dilemmas that Josselson (2007) discusses, but in the context of this study the above discussion around the implicit contract between participant and researcher is particularly valid. The relationship between the participants and I proved to be fundamental to the success of the research. The development of trust and rapport between us played a vital role in the depth and richness of the data provided to me. Hence, throughout the research process I had to be particularly aware of this relationship and my role in it. I needed to position myself authentically and develop real connections with those who had decided to join me in this research. In the words of Josselson: “Ethics in narrative research ... is not a matter of abstractly correct behavior but of responsibility in human relationship[s]” (Josselson, 2007, p. 538). Essentially my own humanness and responsibility towards others were paramount in guiding the ethical attitude required for this study.

3.10 Conclusion

This study’s focus on the lived realities of those who are chronically ill required a methodology that supported and encouraged a narrative expression of those „realities“. I utilised a narrative approach, underpinned by the interpretive paradigm, to guide my choice of data collection methods which complemented the needs and aims of the research at hand. The interviews were in keeping with the narrative approach of the study as a whole and thus were suitable in eliciting rich narratives pertinent to the research at hand. The study’s qualitative orientation and narrative approach allowed for the use of thematic analysis as the primary tool of data analysis. Due to the inherent nature of the study and the methodology I

adopted, I used trustworthiness as a guide in conducting the research and a benchmark to evaluate its worth in a way that was consistent with the principles and assumptions espoused throughout this methodology chapter. The research was guided by ethical principles that upheld the anonymity, confidentiality and autonomy of the participants.

CHAPTER 4: NARRATIVES

4.1 Introduction

In order to understand the experiences and challenges faced by adult learners with chronic illnesses in the context of higher education, I adopted a narrative approach. In-depth narrative interviewing was used to gather data and provide insight into the lives of these learners. Through the use of snowball sampling, I selected four, middle class, English speaking women (two white women, one coloured and one Indian woman), ranging from the ages of early thirties to mid-fifties, from various higher education institutions around South Africa, who are ill with an autoimmune illness. Each woman was currently studying with the exception of one, who at the time of the interview had just submitted her thesis for examination. The year of study that each of these women was engaged in ranged from undergraduate to postgraduate in various disciplines.

This chapter presents each woman's narrative as authentically as possible, organised around prevalent key aspects such as their identity and background; diagnosis and experiences of illness; studies (including motivation and goals) and experiences of learning; work-family-study commitments; coping and support networks; and learning about themselves.

Each narrative, as presented below, is drawn from the in-depth interviews. In order to present their stories in an authentic manner, I had to be aware of my own experiences, assumptions and worldviews which could influence the write-up of their narratives. With this in mind, the sharing of my own story, as a white, middle class, chronically ill student/researcher, is an important part of understanding my own role and influences in this research. It is with this narrative that I therefore begin. My own narrative, as presented below, was reflexively developed through journaling and written story-telling which underwent the same coding processes and analysis as the other participants' narratives.

4.2 Five Stories of Illness and Learning

4.2.1 Michelle's Story

The Ill Student Researcher

It was such a relief when I was diagnosed in 2009 with systemic lupus erythematosus¹. This may seem a strange reaction, but for my husband and I, it was the news we were praying for. We had been going from doctor to doctor for years only to be told that they could not find anything wrong with me or that I was depressed. We knew something was very wrong, but without a diagnosis we were not going to find the help I needed. I began to play detective: researching, documenting symptoms and building up evidence so that someone would believe me. Finally, a doctor did...

I was a sickly child, so for me to be ill was not unusual, but in my early twenties I fell ill with encephalitis² and never seemed to fully recover. I then started to struggle with „bone crushing fatigue episodes“ where, out of the blue my whole body would begin to ache like I had the worst flu of my life and the accompanying fatigue was so severe my eyes would start rolling into the back of my head. I would slur and stutter and it would feel like someone was pushing my head down with all their strength. It was overwhelming and terrifying and it would come on at any time without forewarning. I then developed more chronic symptoms; I had persistent joint pain, I was constantly tired and generally felt terrible. I went from doctor to doctor who performed different tests, but were never able to pinpoint what was wrong. I was generally turned away with some painkillers, antidepressants and a sense that it was all in my head. Then the rashes on my face and ulcers on the hard palate of my mouth appeared, which I fastidiously photographed and added to my arsenal of evidence. After many years of trying to find an answer, I decided to contact a specialist rheumatologist and within the first few minutes of our appointment, after looking through all the blood tests and photographs I had

¹ “Systemic lupus erythematosus (also called lupus or SLE) is a disease where a person’s immune system attacks and injures the body’s own organs and tissues. Almost every system of the body can be affected by SLE” (Carson-DeWitt, 2006, p. 3616).

² “Encephalitis is an inflammation of the brain, usually caused by a direct viral infection or a hypersensitivity reaction to a virus or foreign protein” (Robinson, 2002, p. 1177).

gathered, she diagnosed me with systemic lupus erythematosus. I was not crazy or malingering. I was really sick. It was a small victory. I was immediately put on treatment and now, armed with my diagnosis, I could start accessing the help I so desperately needed. I had proof, but I still struggled to get people to understand what I was going through. Although they all nodded, deep down, I felt they did not understand, or would not understand.

During the time of pre-diagnosis, I had completed my undergraduate degree and was trying to finish my honours. The lupus had significantly slowed my progress and studying was just that much harder. I was forced to take fewer modules and spread my degrees over a longer period in order for me to cope with the stressors and strains of studying. Due to the erratic nature of the illness, I never knew what the next day would hold for me, and so I was constantly pushing myself to do more, to be ahead, never knowing when a flare would take me down. This, of course, was a double-edged sword, as pushing myself would often lead to a flare up of the illness. Studying was a series of starts and stops. I could not sustain a consistent studying regime. I was grateful that my degrees were correspondence based as I would never have coped with going to class each day and carrying those heavy books. It would have been an insurmountable challenge.

Once I was diagnosed I was able to get help from the university in terms of examination assistance. After submitting all the evidence to support my diagnosis, they were able to provide assistance in the form of an exam room with an air-conditioner, a computer to type on and extra time. This helped me immensely, especially in the sweltering heat of the February honours exams. I passed cum laude. Given the circumstances of my illness, it was a significant achievement.

After my honours, I lectured for a year at FET (Further Education Training College), which piqued my interest in education. I decided to enrol for a Masters in Adult Education. I was thrilled to be accepted into the Masters of Adult Education programme and was looking forward to „going to university“ and having access to lecturers and maybe even making a few friends. The novelty of „going to class“ died quickly. It soon became a massive task to find parking where I did not have to walk long distances to classes. I battled to carry my heavy bag up stairs and across campuses. The lighting in the classes became a problem. The UV emitted from the bulbs made my lupus flare. Just two hours under that lighting and I would be crippled with nausea and fatigue. I struggled with reading books. The joints in my hands

would throb as I tried to hold the books open. Writing and taking notes with a pen was awful. Besides the mechanical issues, it took enormous effort to concentrate and absorb the information shared in lessons or in the journal articles we were asked to read. I would often read a paragraph over and over again and could not recall what I had just read. It was and still is a constant battle.

Mid-way through the year I fell pregnant. We were so excited, it was to be our first child, but almost immediately I became extremely ill and ten weeks in, I miscarried. I was broken. I descended into a monstrous flare-up of my illness and I realised I could not continue with my studies. So I completed the suspension forms, submitted them and spent the rest of the year trying to recover. It was during this time that I began to think about what it was like for others, like me, who were battling an autoimmune illness, as well as trying to complete a degree. What were their struggles? How did they cope?

By the next year, with the encouragement and support of my husband, I felt strong enough to continue with my Masters. I spoke with the specialisation coordinator and she suggested that, due to my health concerns, a full research masters which would not require me to come to class per se, would suit me better than the course work masters I was previously registered for. The academic staff was happy with the work I had done in the course work so far and the marks that I had achieved, and thus were confident that I had the skills to undertake a full research dissertation. The coordinator also explained that the full research degree was funded and so I would not have to pay anything. This was a major selling point, as I was unable to work and we did not have very much money. I was paired with my supervisor who, thankfully, understood the challenges I faced and was prepared to work with me.

But as time moved on and I saw the others so far ahead of me, I began to feel panicked. I was so slow. Everything took me twice the amount of time it took the other students. Before I knew it, the year was over and now I had to register for another year. This, unfortunately, meant that my studies would no longer be funded and that I would have to find the money elsewhere. Having experienced help from my prior university in the form of extra time, I reasoned that if extra time for exams could be provided to students with disabilities, surely extra time to complete a degree should be a viable accommodation. I was wrong. I spoke with the UKZN Disability Office and they said they could not help me with that. The funding for the full research Masters was for one year only; no exceptions. Then, the Disability Office

suggested that I apply for disability funding. This became another stumbling block. The way the documents were worded and the information they asked for from doctors was designed for those with visible, stable disabilities. Therefore, the medical forms did not provide my doctor with the room to explain the full nature and extent of my illness. Regardless, we tried to apply anyway, as I was desperate and had no other funds to continue. The cut-off time for registration approached and I still had heard nothing about my application. In desperation I asked my parents-in-law for a loan, which thankfully they could supply. So, without a moment to spare, I was able to register. The Disability Office was able to organise me a „disabled parking“ disc, which really helped in terms of parking close to wherever it was that I needed to go, but after that I had no further interaction with the Disability Office. I felt, and still do feel, that I had become irrelevant and did not rank highly on their to-do list. Perhaps, I am not disabled enough! To this day I have still not heard anything about my application for that loan.

I continued with my research, but due to major financial constraints, I took on four part-time jobs in order to help pay the bills. This, on top of being so ill, significantly impacted on my ability to study. I was exhausted all the time. I felt like I was thinking through mud. My mind felt fuzzy and out of focus and it was extremely difficult to absorb what I was reading. When it came to writing my chapters, each sentence was laboured. Each sentence was written and rewritten as I struggled to find the words that my brain had momentarily forgotten. They call it „Brain Fog“, a typical symptom of lupus. There were days, even weeks, when I would be wracked by pain and fatigue, which would jeopardize any of my attempts to accomplish the small, measured goals I had set for myself... Before I knew it, months had gone by and I had not progressed at all. Another year was drawing to a close. I felt so guilty when I needed to lie down and rest. Inevitably, that guilt and subsequent stress eradicated any chance I had at resting, so I would get up and continue in a daze, accomplishing nothing. Regardless of my husband's insistence that I rest and „take it easy“, I struggled to allow myself this „luxury“. All I could do was take it day by day, bit by bit. I could not focus on the dissertation as a whole; it was too overwhelming. I had to break it down into small steps and it was a task unto itself not to become disillusioned when I could not complete the small steps I had set in the time frame I had expected. There were many days where I considered giving up my Masters, but with the support of my supervisor and the undeniable source of strength and love from my husband who supported me in every imaginable way, I have achieved, in my mind, the unachievable. I completed my dissertation. I have invested so much of myself into this

process. This research has become a large part of who I am and in turn I have become a part of something larger than myself.

Through this process, I have been allowed insight into, not only the lives of others who are chronically ill, but into my own. My somewhat isolated sense of being has shifted to that of shared camaraderie with those who so willingly shared their stories with me. The process has been cathartic in itself and I hope it has been so for those who participated in the research.

4.2.2 Sasha's Story

Sasha is a middle-aged woman who is an academic, an activist, a lecturer, a mother and a wife. She is extremely driven and passionate about her work and dedicates large amounts of her time to it. She recently completed her thesis in Social Justice Education and has submitted it for examination. Sasha's family has a history of autoimmune illness, but she was the first in her family to be diagnosed with systemic lupus erythematosus.

After a few missed opportunities to conduct the interview, due to either Sasha or I being unwell, we finally met up. I met Sasha at her office. If you did not know that Sasha was ill, you could not tell from her outward appearance. She seemed relaxed and comfortable and easily moved into the position of „storyteller“. During our interview together, it seemed important to her that I understood how significant her work is to her and thus „work talk“ dominated the narrative. Sasha stressed times and dates in her narrative, often going backwards and forwards over which year certain events occurred. Her focus on dates seemed to portray a need to have some control over her story. She expressed feelings of a lack of control throughout her narrative. Although Sasha spoke a lot about her feelings, she seldom let them manifest physically in the interview. Her story was told with enormous emotional control. The one or two occasions when she did allow one of her emotions free reign it was usually that of anger.

Finding her way

Diagnosed a few years ago with lupus, Sasha has had a hard time coming to terms with the illness and the limitations it has placed on her. Sasha was extremely busy with work, her activism and her PhD when she noticed that her fingers were becoming more swollen and

stiff which was affecting her work. Initially, she linked it to the back spasms that she experienced from time to time from sitting at the computer, but the swelling was not going away. Sasha decided to see a doctor friend who, knowing that she had autoimmune illnesses in her family, wanted to investigate further. He felt it was lupus. This came as a shock to Sasha. The doctor did numerous blood tests over the course of several months. She was subsequently diagnosed with lupus and put on a myriad of medication.

Sasha continued with work and her studies, but found that it was just that much more difficult. She has a high tolerance for pain, but the chronic fatigue wore away at her: *The thing that I found most difficult dealing with was the chronic fatigue. I could cope with the pain, I could cope with the discomfort; of course the swelling in my fingers at times and stiffness really slowed me down in terms of working on my computer, typing and stuff like that, but what really impacted on my life and on my work was the chronic exhaustion. In that first year I think I never slept so much in my life.*

Sasha spent the first two years after being diagnosed trying to accept and adapt to a new way of being, but found that the lupus held her back in many respects and impacted on who she was: *Those two years, [were] really a matter of coming to terms with having this disease and learning to adapt to it and I found that very difficult because it prevented me from being who I was. It prevented me from doing things that I did before. It prevented me from functioning in the way I functioned previously and that was the hardest part; dealing with that.*

Sasha's illness has had a strong impact on her scholarly work, which is an important part of her identity. Her motivation to study for her PhD was driven by her activism. This degree, for her, was an extension of that activism and an important area of research she wanted to explore. She started her PhD before she fell ill with lupus. When she became more and more symptomatic, this ultimately impacted on her progress. The unpredictability of her illness, the fatigue, and memory and focus issues became major obstacles to her learning.

Sasha had to make choices about what she could put her energy into at any one time. During the process of writing her thesis, she had to put her PhD first, whilst withdrawing from other aspects of her life: *In fact the last six years probably, things were put on hold because the PhD took precedence. So it was my work and the PhD. So I kind of put aside all of that and*

while I did things, you know in little ways, I kind of was working towards getting the thesis out of the way and then picking up on all of my plans.

Sasha tried to adopt certain studying techniques in order to get through her thesis whilst dealing with her illness. When she was too ill to write she would read in bed, but on many days she was too ill to do anything and would mainly sleep. Memory problems would play havoc with her progress, especially when she would forget that she had read certain journal articles and would reread them. Sasha understood that she could not do it all and needed to rest, but the way this made her feel drove her on.

Due to the lupus hampering Sasha's efforts to complete her degree, she opted to tell her supervisors about her illness: *I didn't know where I was going at that point in time. After that, after I learnt that this is what it was, that kind of consumed me dealing with it and coming to terms with it and not being in control anymore.*

Although her supervisors were initially supportive, her relationship with her primary supervisor became strained as she fell behind in terms of her PhD.

Besides her studies, Sasha's illness has impacted on all the other aspects of her life. Work and family commitments have all been affected and in turn have impacted on how Sasha feels about herself: *I felt terrible, I felt useless, I felt like I'm not doing my work... That's how I felt when I couldn't work at my thesis. I felt like I was wasting all this time. I felt like I was lazy, like I was not competent.*

Sasha feels guilty about not being able to work at the level she had done before and the impact her illness has had on others, especially her family. Her role as mother and wife has become more difficult due to juggling work, studying and illness: *I get sad about what my family experienced when they look at me and think about my illness and the times when I'm not myself and I can't be myself and how it's impacted on my ability to do things I could do before. I know that they feel terrible and more than that there is nothing they can do to help me.*

In an effort to feel useful, manage how others view her and have some sense of control over her life, Sasha tries to maintain certain roles: *I sit for days and do absolutely nothing because*

I'm exhausted...the only thing I did was cook. I'm very passionate about cooking, I love cooking. It was the only thing I could do no matter what was happening to me. I'd cook and then go sleep and get up and have supper but that was the one thing that I could do that said "Okay, you can do something", coz it's a strange thing, in a funny way I had to find something that would tell me "Ja, you can still do things". I don't know whether you are the same but I think when I look back now, I had to be in control. You know this feeling about if you don't do it then it's not going to get done right. I was like that.

It is important to her that her illness is not used as an excuse or that others perceive her as making excuses. She is wary of her illness being used against her and so tends to try to do everything herself: *I still do everything in terms of what needs to be done with my work, coz nobody is going to do it if you don't do it and the other important thing that I need to say is that I feel I have to do it because, if I say I can't do it because of my illness, it is going to work against me. I'm going to feel that people will feel, "Oh, let's not give it to her coz she can't do it she's not well". So, I feel like even when I can legitimately say that I can't do this, because I won't cope with it because of my illness, I feel like that it is an excuse and I cannot use it.*

Even at risk of making herself more ill, Sasha still tries to do it all, although she understands that she cannot continue to do so.

Sasha's support networks have helped her cope with her day to day responsibilities. Her family has been her primary support, but with her husband away from home much of the time due to work and a daughter who is studying and has serious health issues of her own, this has not been without its own problems. In the context of work, some of Sasha's colleagues have gone out of their way to assist Sasha in a more practical sense in terms of helping her with her workload. Her secondary supervisor provided not only academic support, but also psychological and emotional support. This, for Sasha, was very important and integral to the successful completion of her thesis.

Where some of her work and academic relationships have been very supportive, other relationships have become problematic. Friction with her primary supervisor seemed to stem from him not really understanding what her illness entailed. Her staggered progress and infrequent contact with her supervisor seemed to create a distance between them and a

waning interest in her research. Sasha, in many ways, felt very let down and abandoned by her primary supervisor. Unfortunately, Sasha also experienced colleagues who used her illness as a way to go over her head on programmes or projects that she was in charge of by painting her as ill and incapable of doing her job. This caused Sasha immense pain and anger, but instead of being defeated, she channelled these injustices into her research and postdoctoral plans.

Sasha's lupus has had significant impact on her sense of herself and on her sense of her relationship with the illness itself. Ultimately, Sasha is still learning to accept that she has lupus, which has been difficult: *I still think that...ugh, someday they're going to say "Oh ja, it was a big mistake, it wasn't really that." I from time to time, still think that but I know it's a part of my life. I have accepted that as part of my life and I have been making changes and adjustments and adaptations. I still have great difficulty coming to terms with how little control [I have]...I still push myself, but I found that when I push myself I kind of take longer to get over that and so it kind of gets back at me .*

Sasha is trying to find a way to move forward with lupus. Although she understands that she is ill, she sees lupus as something separate and alien to her. She struggles to come to terms with it but continues to move forward, shaping a new path for herself: *I don't see it as a part of my identity. I don't! It doesn't define who I am! It's there, it's part of my life. I know that I will have it the rest of my life. I'm going to have to deal with it, but I'm grateful for what I can do and I try not to focus on what I can't do although it gets to me, as I've said. It gets to me because I can't do the things I could do before. I can't work the way I could work before. I can't plan ahead...so in those ways I have had to adapt, had to make changes.*

Sasha has recently submitted her thesis for examination and this has been a great victory for her. There were many times when she felt that she would not be able to complete it, but through the support of family, a few of her work colleagues, her secondary supervisor and her own perseverance, she completed her thesis.

With her PhD out of the way, Sasha hopes to return to her previous projects that were a large part of her activism. It has been a huge relief to complete her PhD and now she has more time and energy for her other pursuits. Sasha is still learning to pace herself, delegate and ask for help, but she insists that she will not allow the lupus to stop her from achieving her goals: *It*

doesn't define who I am. I'm still me. I'm still excited about what I have to offer. I'm still passionate about my work and my activism and right now I'm focused on how that's going to go forward with my plans for my postdoctoral work.

Sasha has not lost sight of where she wants to go and is just as determined, if not more so, to realise her dreams.

As the interview drew to a natural close, we fell back into more relaxed roles as we chatted about my research and compared „notes“ on medications we were both on and symptoms we both experienced. Sasha asked if she could have the transcript of her interview for her own research. It struck me once more how important Sasha's work is to her and how that work is an integral part of who she is. As Sasha and I said our farewells, I felt utterly spent. I had not realised how exhausting and intense this type of interviewing could be.

4.2.3 Josephine's Story

Josephine cannot remember a life without pain. Diagnosed with rheumatoid arthritis³ at 19 and being in her 50's now, she has had more years living with this illness than without. Josephine is married with no children. Although she has had a number of small businesses that she ran from home, she has put aside most things in order to study a correspondence undergraduate degree in theology. Josephine has dedicated her life to God. She has published a number of books and articles, spreading the Word and her testimony to others. She has also set up an online support group for those who have been diagnosed with rheumatoid arthritis.

Josephine came to my home for the interview. I had not expected her to be so physically disabled and was unprepared for her in that manner. I had to assist her out of her vehicle and into my home due to her difficulties with walking. I had set up a spot for her on the couch, but she immediately told me she wouldn't be able to sit there as she would not be able to get up and it would put her in danger of dislocating her hip. I had to quickly find her a high chair

³ “Rheumatoid arthritis (RA) is a chronic autoimmune disease that causes inflammation and deformity of the joints. Systemic problems may also develop, vasculitis, development of nodules (rheumatoid nodules) in various parts of the body, lung disease, blood disorders, and osteoporosis” (Salman, SAlnuaimi, Lateef & Kadhun, 2014, p. 227).

and move all rugs out of the way so that she did not trip on them. Although in obvious discomfort, Josephine was extremely bubbly and quick to laugh. She did not need too much prompting to talk. She laughed a lot during her storytelling, perhaps to ease the seriousness of the subject matter she was talking about. She cried a number of times and was quite surprised by this. Her storytelling centred on her relationship with God. This interview was, for her, an opportunity to provide her testimony.

A journey with God

It came as a shock when Josephine was diagnosed with rheumatoid arthritis. She was an active young woman in her final year studying to be a teacher. When she started to experience pain in her joints she initially thought it was a sports injury, but when it progressed to the point that she was in so much pain that she could not walk to the bathroom, she knew something was very wrong and went to see her doctor. The doctor admitted her to hospital and, after a number of tests, she was diagnosed with RA by a specialist rheumatologist. Josephine was bewildered and scared. Her entire life had been turned upside down: *I thought arthritis was for old people (laughs). So, at 19 I was totally ignorant of the situation and it was very fearful. You know, to go from playing squash, active at college, studying to being bedridden... Um, because it had sort of progressed over the months where in all my joints throughout my body...and that's what rheumatoid arthritis is, it is a systemic disease, it affects your whole body.*

Josephine did not go back to college except to write her exams, which she passed with the help of her friends. She graduated early the next year.

It was a tumultuous time in her life, but it also was the catalyst that reignited her relationship with God. This became her greatest coping strategy. The strength of this relationship has helped her cope with the challenges of living with rheumatoid arthritis and other difficulties in her life. However, although her relationship with God helped her in many ways and continues to do so, it also caused strife and derision in her family life: *I discovered a new world and I discovered the spiritual side to me, it came alive. So that was quite remarkable, but it was also very traumatic because my parents didn't understand.*

Her family were not Christians and her continued need and desire to worship and learn about God, especially after the initial diagnosis, placed strain on her relationship with her parents and siblings. Although having an active relationship with God brought her great comfort and ability to cope with her illness, the continued rejection and friction caused by this within her family forced her to behave in a way that her parents wanted. Over time, this led to Josephine's complete estrangement from them. She remembers a particular moment of crisis in the relationship: *So a turning point came one Friday evening I came home from youth. I used to come home with a combi to pick me up and I came home and my brother and his wife had come down for the weekend and my parents were there... I was very sick, but I was incredibly joyful... But unfortunately it worked against me because they accused me of...drinking and taking drugs. I was a very good prim and proper young girl (laughs). I led a very sheltered life and so to be accused of that was so traumatic, by not only my parents, but my brother and my sister-in-law had turned against me and that was a turning point. I cried myself to sleep that night. I was so traumatised and unfortunately I stopped going to church. It was the worst decision I ever made and I landed up almost...for almost seven years staying away from church.*

Although she stopped going to church and withdrew from her relationship with God, it seemed the damage was done and her relationship with her family continued to deteriorate.

Josephine's illness also had an impact on her professional life. She went on to get a job as a teacher at a primary school and worked there for a few years. The headmaster was very accommodating and tried to make it easier for Josephine to work, but eventually it became too much. After two and a half years, Josephine was medically boarded. This was devastating for Josephine. She loved children and she loved teaching: *So along with a loss of health and loss of family, I lost my ability to earn a salary and to work and the very thing I loved (teaching).*

Josephine spent her 21st birthday in hospital having both of her knees operated on. It was during this time, in physiotherapy, that she met her husband, George. He was an outpatient. The physiotherapist, playing matchmaker, made their appointments for the same time every day. Their relationship blossomed quickly and not much later they were engaged and then married.

Their relationship was met with resistance from both her family and his. Josephine's family gave her an ultimatum and demanded that she choose either them or the man she had fallen in love with. His family were very concerned with Josephine's health and brought in a doctor to talk to George about how seriously ill she was and whether he was prepared to have her in his life with all of these issues; but this did not put him off. They married and have been together ever since. Throughout the years her husband has been an integral part of her support system: *He's always been able to see beyond the disease which was really important, because many people, when you get a disease as dramatic as that which affects you so badly, you almost lose your identity and they just see you as „rheumatoid arthritis“ and they somehow treat, not intentionally, but they sort of treat you a little bit differently. But George has always just treated me as though I was absolutely normal which really has helped me, you know... George has never made me feel a burden, you know. I've cost him a lot of money. He had to get an extra job to pay but he's never made me feel a burden, a financial burden, which... I know other ladies; their husbands have walked out on them because of the burden.*

Through many operations and lengthy stays in hospital, Josephine found herself drawn back to God whom she made a priority in her life. Over time, her husband also committed himself to God and ever since, they have served God together. This solidarity and interconnectedness with each other and God has been a source of strength for Josephine. Josephine has coped with many of the difficulties that she has experienced due to being ill by understanding them as God's purpose for her, including the consequences for her family and professional life: *So yes, God has been my main help, but George has been the sort of hands and feet to help me practically, and to...although I've had a tremendous amount of suffering, um...to be happy and joyful through it all, which you know, without God I probably would land up being quite bitter and you know because on top of the loss I also lost my ability to have children and being a teacher... Um, I wanted six children. Aren't we glad that God doesn't give us what we want (laughs)? I just think six children! But that is what I wanted, you know. I loved children. So I had to battle for quite a few years [until I] eventually surrendered to God.*

This surrendering to God has not only been an important coping mechanism, but has also guided her decisions in life. That is how she came to study theology, now, much later in life. Josephine and her husband feel that God guided her to study theology and this is part of His plan for her, but even though she feels that God wants this of her, she does have her doubts about her ability to study: *I was very nervous too, you know, in 2012. I was into my fifties*

already and...um; the one thing I was very worried about was I'd had about thirteen surgeries, so many anaesthetics. I was convinced the anaesthetics kill off your brain (laughs). So, I wouldn't say I thought I was stupid, but I was really worried about my memory more than anything. Whether I would remember things and whether I had the capacity to remember enough to write exams. That is what I was worried about.

Josephine has always kept herself busy with numerous jobs, helping at the church, writing and volunteering whilst doing all her own housework and cooking. Now, though that she is studying, most, if not all of her energy and time has had to be focused on her studies in order to cope and in doing this, other aspects of her life have had to be put aside: *I realised I couldn't do everything and I think the way I am I find it very difficult to divide my attention with too many things. I'm very much a person, if I focus on one thing I focus on that and don't ask me to do something else. So, for the last two years I've definitely given studying my top priority... I've had to cut down on other things that I would have done...gone for coffee with friends. Quite a lot of my socialising has had to be put on the back burners and I'm hoping I'll still have some friends at the end of this... It's been, I wouldn't say strained, but I think it's been hard for other people to understand that I have to prioritise, otherwise I'm not going to do this, so it's been a little bit hard that I...because I do like the company of other people, but I definitely had to cut that because I know my limitations.*

Josephine tries to be very structured in her studies and tends to do most things such as assignments ahead of time, because she knows that anything can happen: *I've always made sure... I'm a bit neurotic about getting a head start because I know. You see, I can't be like other students who... "Well I've finished this semester, I've got two weeks holiday until the next semester starts" ...and Josephine doesn't work like that (laughs). As soon as I've sent in the last one (assignment) and I've finished, I start the next one...um, because I'm very conscious, I need a head start in case something happens and I'm not being pessimistic, but realistic, because I know that things can take me out.*

She walks a fine line between trying to complete her degree as quickly as possible, but without overloading herself. Stress, whether good or bad, often exacerbates her illness and so, the longer she submits herself to the pressures of studying, the longer she places herself under that stress. At one point, Josephine took on three subjects for the semester instead of her usual

two, which left her overwhelmed and ill. Even though she passed them all very well, she had depleted her physical, emotional and psychological resources.

Josephine had to reassess how she was approaching her studies and day to day life. She had to give up her one business and she contacted the university to tell them about her situation in order to reduce her workload. The university was extremely supportive and understanding. She has now slowed her pace and it has become more manageable and enjoyable. She has also drawn upon technology to assist her in her studies such as using an iPad to get through all the reading required for her degree. The iPad enables her to climb into bed and read without struggling with holding a book open and turning pages.

Mostly, Josephine studies in faith. She does not know exactly which path God is leading her down, but she feels that God has a plan for her. Josephine has written a number of books and articles based on her experiences and understanding of God. Her illness, she feels, has been part of God's plan as a way to connect with others, to provide her testimony and inspire others. It has often been a source of inspiration for her writing. Josephine has embraced her illness as an integral part of who she is, even though this is an unpopular view of illness within the Christian community. Her journey with illness has been a spiritual one: *I would say, purely because of God's influence on my life, that rheumatoid arthritis... I actually say it in my book...has become my greatest blessing for the single reason that it brought me to Him. I live that scripture knowing that my best is yet to come and what I am experiencing now...God is working. Undoubtedly, He's changed my character. I am not the same person I was and a lot of people are very afraid of suffering and I'm not... You have to be convinced that God loves you to distraction. You are the apple of His eye and, as His child; He will give you the best even if it doesn't feel the best. Lupus does not feel like the best, rheumatoid arthritis does not feel like the best, but in God's hands it's the best long term because the character he's developing in you... I'm blessed despite the difficulties and I've found joy in the Lord and I've found a purpose in my life.*

Once the interview ended, we chatted informally. Josephine was quite surprised that she had so much to say. She seemed to have enjoyed the interview. I helped her back to her car. She seemed to be stiffer than when she arrived, most likely due to sitting still in one position for so long, but she did not complain. It struck me how incredibly strong and positive Josephine

is. She truly seemed to be grateful for everything in her life without any bitterness or resentment. It was quite clear to me that Josephine had found peace.

4.2.4 Vanessa's Story

Vanessa is a professional woman in her mid-thirties. She works in law and is studying an undergraduate law degree via correspondence. Vanessa is separated from her husband and, due to financial reasons, has had to move back in with her parents. Vanessa has been diagnosed with lupus.

Vanessa and I had emailed back and forth over the course of a few months. When I first contacted her, she was writing exams and could not see me, but when she completed them we were finally able to meet. She had taken the morning off from work to come and see me. She was immaculately dressed in a stylish pants suit with perfectly groomed hair. She immediately struck me as a confident, independent, powerful woman. I felt quite intimidated. I welcomed her into my home. She told me she would like to take cigarette breaks from time to time and I explained to her that this was her time and she was in charge of how the interview would run. This seemed to satisfy her. She did not smile very much and appeared guarded. I was concerned that she would not open up to me like the others had, but I was wrong. As soon as we started she needed little prompting to talk. She spoke openly and honestly, dropping her guard and allowing herself to be vulnerable with me. Her narrative centred on her relationships, or lack thereof, and the continual suffering that she has to endure each day to achieve her goals.

„I've got to do it in bits“

In 2007, Vanessa was happily married and trying for a baby. When her ankle started to swell and then her knee, she realised something was not right. She went from doctor to doctor and after seven months she was finally diagnosed with lupus. This came as a massive shock and, for her; it felt like a time limit had been placed on her life. She felt a pressing need to do all the things she ever wanted to do such as travel and get a degree, but being married prevented her from doing certain things and that created a lot of tension in her marriage. In retrospect, she felt that if she had been given proper counselling, she would have avoided some of the pitfalls that she fell into.

For Vanessa, being diagnosed with lupus was a death sentence which launched her into an identity crises. Vanessa and her husband drew further and further apart. After being offered a job in another province, her husband left and this seemed to be the final straw, bringing an end to any hope of reconciliation.

For a while, Vanessa's husband continued to pay the bills so that she could still live in their marital home, but this financial support eventually whittled away as their relationship became more estranged. This left her in a dire financial position. As she was only earning a small salary, it became impossible to continue living in her home. She had to move back in with her parents and rent out her home in order to try and keep it. Living with her parents has been fraught with difficulty which, in turn, has created a very stressful living environment. This has highlighted for her more than ever that the only person who can protect her is herself. This has provided additional motivation for her to study in order to secure a higher paying position that would provide her security and a standard of living that can cater for her needs.

Vanessa has always known that she wanted to study, but the diagnosis of lupus was a catalyst for her to begin a degree in law. This degree took on more importance, as her need to increase her earning potential became more prevalent after the separation from her husband and her moving back in with her parents.

Vanessa has taken longer than usual to complete the various stages of her degree, due to the unpredictable nature of her illness and the compounding factor of stress: *I try to be ahead of schedule because of the fact that there's been many times when exams approach and I'm stressed about that or stressed about my husband, that I've landed...twice actually...that I've landed up in hospital and I had to just defer those exams. I couldn't write that. That's why I've also taken many, many years to do this because there's so many, I can't anticipate, I don't know what could cause what, how, when...and I'm sick. So, doing the degree has been very challenging with that, because (sigh) you can't..like, even something like a stressful situation just manifests within my body so quickly.*

Not only is studying for exams difficult for Vanessa, the actual mechanics of writing her exams is a major challenge due to the lupus and its effect on her joints: *I always end up writing and it's a very painful experience and I sometimes even cry during the exam coz it's so sore.*

In order for Vanessa to successfully study, pass her exams and ultimately get her degree, she has to plan her life around her goals. She has limited energy and time and for that reason other areas of her life have had to take a back seat. She tries to be ahead of time with respect to her studies or assignments, due to the unpredictability of the illness. She never knows when it will flare, which inevitably, for that time period, incapacitates her.

Vanessa's reflections on one particular social invitation throws light on what it means for her to be a student with a chronic illness and how this affects her student and social life: *I was invited to a high tea; a high tea at one of the hotels and all of my friends were like, "No, but you must go", and I said, "I can't go", so they said, "Why?", and I said, "Coz I'm writing in a week". I had just written one and I had a week until the next subject, and they're like, "You've got a whole week". For them they'll be like four, three, four days maybe before they will like really get onto it, but for me, I needed to work on it because I might not have twelve hours that you have, maybe I've got about eight or whatever the case. I have to know that I can't max myself out because I've got to do it tomorrow, got to do it the next day. I've got to do it in bits, I feel I have to break up everything into bits and pieces and I can swallow it like that because I can't do it like the next student, so to speak.*

There's so many times where it doesn't matter what my mind tells me and what I know I need to do, I can't and it's...that's just your tough luck and you lose it, you lose that time. So, you've got to try and work around, make it up or you got to decide what's more important to learn. "What do I need to do?" That's why I can't afford to put myself in a predicament where I've only allocated myself a certain amount time.

For Vanessa, getting this degree is an act of preservation. She feels that she cannot rely on anyone and needs to fend for herself: *I have to see it through, and for me, a lot is riding on this. I'm really unhappy in my living situation and there's nobody that I can ask to change it, you know, I can't. I don't have this husband where I can say, "Hah, I hate where we're living, can we do this to make it better?"*

Perhaps the most difficult aspect of Vanessa's life is the lack of support she receives in terms of her illness and her general life goals. At work, although her manager is aware of her illness, she is not particularly understanding and accommodating. There are many frustrating aspects such as not being allowed to park in the parking spaces close to her work which have

been reserved for the managers, having to physically carry files from floor to floor of the building. These things make life just that much harder. Although she has certain struggles at work, she prefers it over her living space with her parents. She often stays at work, late into the night, in order to study. Living with her parents has been challenging. In the room provided for her there is no desk. She is not allowed to use a heater due to electricity costs and the geyser is switched off at inconvenient times. Vanessa finds that sitting on her bed to study does not work and being cold exacerbates her joint pains, making studying very difficult. Vanessa feels that her parents are not as supportive as they should be: *It's my understanding that a parent would want to do everything and anything to make their child comfortable.*

Added to this, Vanessa also tends to withdraw from others who could possibly help her when she is in pain. When she was first diagnosed, she felt ashamed, and now, although she feels that that sense of shame has dissipated, she still will only allow certain people to be around her when she is ill and in pain: *I find it to be very humiliating when I'm flared up or in any sort of pain. Initially, there was a lot of shame that I felt with the disease. I didn't want anyone to know... Now I'm not, I'm fine with telling people, but when it comes to me, actually experiencing pain, I don't want anyone to see.*

Due to Vanessa having very little social support, she has learnt to rely on herself for support as a form of coping. She uses „self-talk“ to try and cope with difficult tasks such as pursuing her studies and reaching her life goals: *Like there's times where I'm studying, I'll just cry because it's sore and I wished I didn't have to do this and it's not his hard for other people. I tell myself, "but you want this, you want to achieve this, you have to do this, you have to get through this module, just this module", just like, I break it down per module; not per semester, not per year, just per module. "Get through this module and it is one more down", and it's what I want. I could very well say, "Okay, well I have lupus and it's my life and I can't do this and I can't do this and I won't be able to do this", you know, and then limit myself in such a way. Yes, lupus does limit me too in a lot of ways, in a lot of areas in my life, but this I feel that I can do and I, because it's such a goal, it's my, it's what I have to do... It's the only way I'm going to survive. Then, it's not that it becomes easier, but it's that I'm more determined and I know that I have to work harder. I know that I have to put in more than the next person. I want it so badly. I don't want lupus to be the reason why I don't... I can't get it (her degree).*

Vanessa feels that the lupus is very much a part of who she is, but she is adamant that it will not defeat her or prevent her from doing what she wants to do in life: *It's so much a part of me. I think that even doing masters and wanting to get where I want to be, I want to do it despite the lupus. It is definitely so much more challenging having it...it's so much more challenging, but I still want to achieve what other people can achieve. I don't want to be that it, because of that, I couldn't. It just means that I've got to work so much harder.*

Vanessa has gone through a number of major life changes whilst grappling with illness and studying. Through this, Vanessa has grown and changed, becoming more determined and independent, but also isolated: *I think that, like no matter how difficult it is...studying, I look at it as my way to a more comfortable life with the lupus. I want to have certain things that I don't ever have to compromise on. I want to have a house, like a housekeeper that's going to look after me. I want to have whatever heating I need to have, so I've got to be able to finance that. I need to study to get to some kind of job where I can do that. So, as challenging as it is, and as much as I want to cry sometimes, I have to do it. I just have to. I don't have a choice... I know that like, when I look at myself and my future I know that I am going to have to do everything on my own. I know it's just going to be me.*

Our interview ended and we continued to talk. She asked me a lot of questions about what it was like for me to have lupus and was very interested to hear my own experiences. She expressed what a difference it made talking to someone who truly understood what it was like to be ill with lupus. It struck me, that for her, living with lupus has been quite a lonely journey and that she has not had a lot of people to talk to. I was glad that I could be one such person for her.

4.2.5 Annah's Story

Annah is a busy, middle-aged mother, wife and owner of a nursery school, who is seriously involved in Christian ministry. Annah is currently studying for a diploma in theology via correspondence. Due to distance, our communications were through email. This had many challenges. Although I believe that Annah shared honestly and openly, it was difficult for me to get a sense of Annah as a person. Using email as a mode of interviewing was not particularly conducive to uninterrupted storytelling. This resulted in a question-answer format that was not ideal. Annah's answers were concise and to the point which, although answering

the questions, did not provide any more information than that which was specifically asked for. From the previous interviews, it was the storytelling that was not directly related to the question or topic that often revealed the most about that person's identity. The faceless nature of the interview also made it easier for Annah to gloss over certain aspects of her story, regardless of my probing. The email interview was conducted over a number of days with breaks in between questions and answers.

Seize the day

Annah had in the past struggled with a few medical issues, but, due to their erratic nature and Annah not disclosing all the symptoms to her doctors, she was always treated symptomatically and no coherent diagnosis was made. This was until things started to take a turn for the worse.

Annah began to lose function in her legs and would periodically fall. She was frequently in pain, fatigued and her functioning in her arms also became an issue. She was told that she might end up in a wheelchair. At this point she decided that she had to start thinking of a different career, as she wouldn't be able to cope in her current one as an owner of a nursery school: *So I started studying psychology. That was something I could do from a wheelchair. I pushed my studies. I was grateful God had given me a good brain, because my body was rapidly failing me and I was going to need a new career soon.*

Around this time, Annah finally revealed all her symptoms to her GP, who suspected she had myalgic encephalopathy (ME), also known as chronic fatigue syndrome⁴. To confirm this, she was sent to a neurologist and admitted to hospital where she had a battery of tests and was diagnosed with ME and fibromyalgia⁵. She was given medication and treated

⁴ "Chronic fatigue syndrome (CFS) is a condition that causes extreme tiredness. People with CFS have debilitating fatigue that lasts for six months or longer. They also have many other symptoms. Some of these are pain in the joints and muscles, headache, and sore throat. CFS does not have a known cause, but appears to result from a combination of factors" (Rizzo, 2002, p. 801).

⁵ "Fibromyalgia is described as inflammation of the fibrous or connective tissue of the body. Widespread muscle pain, fatigue, and multiple tender points characterize these conditions" (Larson, 2002, p. 1326).

symptomatically, but it didn't really help. Then Annah deteriorated further. She became forgetful, get lost driving to familiar places, forget her children's names, sometimes even her own name. Annah had to give up studying, as she couldn't cope. Her husband quit his job to take care of her and help her keep her business running, as it was able to bring in more money than what he could. To keep up appearances, her husband would carry her into work in the morning to do the necessary things to keep things going and then he would take her home to bed. Although the staff knew she was ill, she did not think they understood how ill she really was. Many of the parents of the children who attended the nursery had no idea that she was ill at all.

When Annah started to have seizures, she had to go back to hospital, where they ran another extensive battery of tests. Her initial diagnosis remained the same, but now osteoarthritis, rheumatoid arthritis, brain lesions, an ovarian cyst and diabetes were added to her long list of diagnoses. She was discharged with some medication, but with her medical funds exhausted, they were now faced with a desperate situation: *I saw the despair in the eyes of my family, so I prayed. I told God. Yes, told, not asked. He would have to heal me or I would die. What I really meant was I would kill myself because I couldn't continue to live like this. I couldn't allow my family to suffer the way they were.*

Slowly over time, through taking her medication and just trying to take each day as it comes, Annah began to improve to the point where she could spend more time out of bed and go out for a little bit in a wheelchair. Eventually, she recovered enough to work half days during her „well“ periods.

After two years, her husband was able to return to work and Annah was feeling strong enough to study once more. This time, though, her motivation to study changed from studying something that would give her an alternative source of income, to following her calling to become an ordained priest. She knew that she could not take on a full degree again, so instead, she opted for a certificate course through distance learning. This went well, so by the next year she took on another certificate course and subsequently upgraded to a diploma. Due to Annah's health, she could only do one or two modules a year and those modules were chosen whether they were exam based or assignment based: *Because of my poor memory I worry about the exams. I have written and passed, but the stress incurred causes relapse and is just not worth it.*

Annah now juggles work, family and studying whilst grappling with ill health. She tries to get in three hours a day of studying, but this is not always possible. After working in the morning, she is often too tired to do anything and instead sleeps. She continuously has to adapt her day to how she is feeling. The most frustrating aspect for her is the effect illness has had on her intellect: *There's a joke on Facebook, "of all the things I've lost, it's my mind I miss the most". I actually feel saddened whenever I see that. It sums me up perfectly. I can deal with not being as physically capable as most people, but the loss of intellect kills me.*

For Annah, there is a struggle within herself as to how she divides up her time and her attention. This leaves her conflicted, as she has limited amounts of energy which need to be divided up between her family, her work, her ministry, and her studies. This has forced her to change aspects of herself, her independent nature, to someone who can ask for help. Through illness, she has come to learn a lot about herself and others and, in turn, has developed certain coping mechanisms and attitudes that assist her on a day to day basis: *I have learnt to ask for help. I am by nature fiercely independent. I am also a „fixer“: I feel I need to fix everyone's problems for them. I know now that I can't and that it's okay for others to take some of my load occasionally... I have learnt to say no and not take on more than I can deal with. I have learnt that I am human and can only do so much. I've learnt to rest more, which is really important. I've learnt to delegate responsibilities to others and that I'm not the only person who can do the task properly.*

In order for me to cope I have, to a large extent, had to change who I am. I can't push myself as hard as I always have. For the first time in my life I failed an assignment last year. It was the best thing that ever happened to me, because the ground didn't open up and swallow me alive. I still try my best and only once have I not had a distinction for a module.

I've learnt to do, when I can, try at all times and when I can't, admit it and give myself a break... Best of all, I've learnt to laugh at myself, to not take myself so seriously. In conversation, I will sometimes forget what word I'm trying to say and say something else. I hear the word and know it's wrong, but don't have a clue what the correct word is. The other day I asked my husband to switch the umbrella off...light switch...you can't take yourself seriously when you do silly things like that.

Annah's family also functions as a major support system, enabling her to cope. She is deeply grateful for them but struggles with guilt over the hurt her suffering has caused them and the

things she has been unable to do with them. Her roles as a wife and as a mother have been deeply affected by her illnesses: *I try to maintain a positive attitude. That doesn't always work. I'd love to remember how it feels not be in pain. I'd like to remove the hurt from the eyes of my family when they see me suffering. I'd like my husband to touch me without wondering if he's hurting me. I regret missed opportunities, things I couldn't do with my daughters especially... I felt useless. I felt like a bad wife and mother because I could do so little. I've come to terms with it now. I have times when I feel useless and I often marvel at how my husband has stuck with me. I am blessed. I am able to do most things on most days.*

Although Annah recognises that there are times when she will need to ask for help, she will not easily disclose her illnesses to others. There have been instances when she has tried to disclose to others and was met with a less than supportive reaction. In fact, for Annah, it is often just easier not to disclose at all: *When I was first diagnosed I tried to explain to my mother-in-law what was going on. I gave her a book explaining the symptoms. She got to the first paragraph, which spoke about chronic fatigue and said she clearly had this too because she also gets tired. I took the book away, said "Never mind mom", and never spoke to her about it again. When I started with seizures she got an inkling of how ill I was, but never truly understood and I never had the energy to keep explaining. It's easier for me just to get on with life.*

This hesitancy to disclose has impacted not only on her personal life, but also on her ability to access help in her studies. Annah's bishop is on her college's board. Her fears of evoking or experiencing prejudice have stopped her from disclosing to the college and accessing help with her studies. Being ill, in her mind, could be used as a weapon against her. She is acutely aware that prejudice against females working in the ministry is prevalent. Annah feels that to be female and ill would create even more barriers to her working in the ministry: *The less ammunition people have to use against me, the happier I am. My college is unaware of my chronic illnesses, as my bishop sits on their board. He has been told, but I don't know that he remembers and I try not to give him any reason to remember. I don't share about the illness unless it's really necessary for me, or if it will help someone else to know about it.*

Although she has much to bear, her attitude remains positive and she can also see the good that has come from being ill: *My illness has given me more compassion for others and, strangely, inspired others in perseverance, so it's not all bad.*

Despite the many obstacles in her way, Annah has taken on multiple responsibilities and roles that would be taxing for anybody. Her determination, despite being ill, is very clear. Annah will not allow her ill health to defeat her and seems to want to prove to herself, and perhaps to others, that she is still vital, capable and so much more than her illnesses: *I live a very busy life. I live a fuller life than many people who are not ill. Maybe I do this to prove that I still can, or maybe it's what I love to do. I can't decide. This is my life. There is no dress rehearsal. We only get one shot at it so I need to make the most of every opportunity that comes my way, especially because I don't know how long I'll be able to.*

Our interview did not end in the traditional sense. We continued to email back and forth, especially over aspects of her story which I wanted to get a bit more information on, but we also emailed just to see how the other one was doing. This interview was by far the hardest one for me. Annah strikes me as an extraordinarily strong woman, but for me she still remains an enigma.

4.3 Conclusion

This chapter endeavoured to share the participants' narratives in a faithful manner. The narratives touch on key features such as the participants' diagnoses and backgrounds, their identity, aspects of learning and their relationships, coping skills and support systems. Difficulties with learning, complexities in developing and maintaining relationships, identity issues and the psychological impact of illness are common threads that run through the narratives. Pain is a strong crosscutting theme, not only physical, but also emotional, spiritual and „psychic“ pain. Uncertainty, fear, guilt and doubt are prevalent in most of the narratives. In the following chapter, these threads, themes and key features are examined using the theoretical frameworks identified in chapter two.

CHAPTER 5: ANALYSIS

5.1 Introduction

This study set out to understand the experiences and challenges faced by adult learners with „hidden“ disabilities in higher education. To gain further insight into these learners“ life-worlds, a narrative approach was used. Through the process of thematic analysis, predominant themes and patterns emerge from the narratives. This chapter analyses and discusses these themes and patterns, using the theoretical frameworks, discussed in chapter two, as analytical lenses to provide insight and understanding.

5.2 The Interactional Disability Model

According to the interactional disability model, disability is multifactorial and interactional. It stems from a complex interplay between social and physical barriers, individual intrinsic factors such as severity of impairment and extrinsic contextual factors such as a non-supportive or prejudicial environment (Shakespeare, 2006). In sum, disability stems from a dynamic interaction between physiological, social and psychological factors (Rule & Modipa, 2011).

In this section, the interactional disability model is used to explore some key themes that emerged from the data.

5.2.1 The Interaction of the Physiological and the Psychological

Themes of pain, illness and stress dominate the narratives and demonstrate clearly the debilitating role chronic illness plays in the participants“ day to day lives. On a physiological level, illness creates enormous barriers in terms of learning, but it seems that these barriers also impact psychologically, further creating a debilitating cycle of stress, exacerbating illness, which becomes difficult to escape. Below are illustrated some of the symptoms of chronic illness in relation to learning and the psychological consequences thereof.

All of the participants mention exhaustion as a symptom that undermines their learning. These difficulties are reflected in the narratives shared by the participants. This is detailed in my own narrative: *I was exhausted all the time. I felt like I was thinking through mud. My*

mind felt fuzzy and out of focus. It was extremely difficult to absorb what I was reading. When it came to writing my chapters, each sentence was laboured. Each sentence was written and rewritten as I struggled to find the words that my brain had momentarily forgotten. They call it „Brain Fog“, a typical symptom of lupus. There were days, even weeks, where I would be wracked by pain and fatigue, which would jeopardize any of my attempts to accomplish the small, measured goals I had set for myself... Before I knew it, months had gone by and I had not progressed at all. Another year was drawing to a close. I felt so guilty when I needed to lie down and rest. Inevitably that guilt and subsequent stress eradicated any chance I had at resting, so I would get up and continue in a daze, accomplishing nothing.

Sasha's story also demonstrates how exhaustion impacts on concentration: *You just disengage and you disconnect with what's happening around you because you're not concentrating, you're not focusing, you're just exhausted.* Annah expressed similar struggles with exhaustion and learning: *I don't have a typical day. I try to get in three hours study a day. That's my goal, but it seldom happens. I work in the school until about twelve. By then I'm exhausted, so I have to have a sleep... On a bad day I sleep until bed time and then sleep some more.* The associated chronic fatigue experienced by the participants has created hindrances in their ability to learn and, subsequently, on their ability to cope.

Stress and its impact on learning and illness is an overarching theme throughout all of the narratives. Both Josephine and Vanessa point to the manifestation of stress in their lives and its intricate relationship with illness and learning.

Josephine experiences „bad stress“ days, which render her dysfunctional: *If I have bad stress, the next day I'm in bed for the day. I can't function. I know I'm willingly putting myself under stress to study... I [want to] keep it as compact and the time period as short as possible so as not to prolong the stress.* Vanessa experiences acute physical stress during exams: *I hate a flare up. I hate when everything else doesn't work and with exams it's been very difficult... I always end up writing and it's a very painful experience and I sometimes even cry during the exam coz it's so sore.* This sentiment is echoed by Annah: *I have also had to choose subjects according to which are based purely on assignments and which have exams. Because of my poor memory I worry about the exams. I have written and passed, but the stress incurred causes relapse and is just not worth it.*

The above excerpts illustrate how exhaustion, pain and the psychological impact of stress disrupts and delays learning. This has a powerful impact on how the participants feel about themselves. Experience of pain (*“I would be wracked by pain and fatigue”*) and guilt over not being able to complete the work timeously (*“I felt so guilty when I needed to lie down and rest”*) creates further stress and so obviates the possibility of true rest. These experiences reveal how the interaction of physiological and psychological symptoms can potentially disable the person and their learning.

There is a sense of „unknowing“ that is threaded throughout the narratives. This unpredictability has significant consequences on how learning is approached. Additionally, the instability of the illness breeds feelings of angst, loss of control, doubt and uncertainty. It, undoubtedly, adds to the stress experienced by the participants. Vanessa’s narrative reflects this: *I can’t anticipate. I don’t know what could cause what, how, when...and I’m sick. So, doing the degree has been very challenging with that, because (sigh) you can’t...like, even something like a stressful situation just manifests within my body so quickly.* Sasha’s narrative has similar sentiments: *When my lupus started it just (pause), you know, impacted so significantly on my PhD, which took me much longer than I anticipated and I...you know, there were important times when I even questioned whether I was even going to get to the end of it.*

Their bodies have in many ways become a hindrance to the learning experience. The above excerpts demonstrate how the physical manifestations of illness hinder their learning and how the stress of learning can impact on the illness itself. There is a dynamic interaction between the two.

5.2.2 The Interaction of Contextual Factors

According to the interactional disability model, the social context plays an important role in the enablement or disablement of the person in question. As relationships are an integral aspect of our social worlds, relationships that are mediated by illness can result in either a supportive social context or one that creates further barriers.

On a physical level, illness limits energy and thus impacts on how many activities the affected person can sustain, on their interactions with others and on their social world as a

whole. My personal narrative demonstrates this: *I don't go out. I seldom visit friends. I know that I have limited energy. So I am constantly making choices between doing housework or going to buy groceries or working or studying. I struggle to do more than one of those tasks in a day. When I do make time for fun activities, I know that I will be „out of action“ for several days afterwards. I have to make allowances for that.*

Sasha reflected, in her narrative, how she had to give up other aspects of her work and activism, which were extremely important to her, in order to focus on completing her PhD: *So there's always been that passion and that excitement there, but for the last six years I've not thought about any of that and worked with any of that that I'd initiated. So that's all been kept aside.*

Josephine has had to sacrifice many of the social activities she was previously involved in. She has even had to withdraw from attending bible study, an incredibly important activity associated with her goals and perceived purpose in life: *It's been, I wouldn't say strained, but I think it's been hard for other people to understand that I have to prioritise, otherwise I'm not going to do this. So it's been a little bit hard that I, because I do like the company of other people...but I definitely had to cut that because I know my limitations. Normally we would go to a Monday night bible study and that we've actually, sadly, had to cut out, because if I'm studying all day, by the time it is evening I haven't the energy to get ready and then go out to the bible study.*

Vanessa, not only sacrifices on a social level, but also has had to use all her leave for studying purposes. Instead of taking time off and relaxing, she uses that time to push ahead in the pursuit of her degree: *I haven't really felt very capable of being able to do everything and anything and there's a lot of times, socially, I decline a lot of invitations, because it's just...it's just too much and people don't really understand that for me to work a whole day and come home and then go and do something for a night...it's so difficult and they, um...maybe they think I'm anti-social or whatever, but it's...it's fine because I know what I have to do to take care of myself... I try and save my leave so I take off quite a bit of leave from work. We get study leave, we get one day preparation and one day for the exam and I use my annual leave in between. I haven't had a holiday in years. Annah too, touches on the issue of limited energy: *I will never stop wanting to do many things; I just know that I only have a limited amount of energy, so I need to use it wisely.**

Striking, in all these excerpts, is how experiences of illness circumscribe social interaction, especially when participants try to conserve precious energy resources for their studies. This „non-interaction“, or metered involvement with others and their inability to fulfil all of their responsibilities, can potentially weaken critical social bonds that can provide a supportive network. This particular interaction between the intrinsic physiological and the extrinsic social can lead to disablement. As seen in the above excerpts, the participants all shared that, due to their respective illnesses, they have had to limit or stop many of their activities, especially in relation to their study load. Relationships with friends, family, colleagues and academic relations have all been affected. There is a sense of withdrawal from others and, in turn, this creates isolation and aloneness. It also hinders understanding and the perception of their particular illnesses. The peculiar hidden nature of these types of chronic illnesses can often exacerbate potential for misunderstanding and prejudice.

The following extracts, related to the crucial social move of disclosure, further illuminate this phenomenon. Here, I reflect on my own experience: *Revealing my illness to some people was met with suspicion. They did not know what lupus was and it wasn't as though I looked sick. Even when I sent them information about it, this didn't seem to sway them or perhaps they never really read it. With such low energy levels, they perceived me as lazy. I was even told that they had very little sympathy for me and that I must „suck it up and get on with it“. This hurt me deeply. I continued to push on as best as I could and tried not to show them how „weak“ I really was. This impacted on me so profoundly that to this day I struggle to rest even when I desperately need to. I am so overcome with a sense of guilt and uselessness that I struggle to allow myself to rest, to be „weak“. Their perception of illness and how it should be handled has stayed with me and has become the little voice in the back of my head that tells me how useless, weak and lazy I am every time this illness overwhelms me. It is a dark and difficult mindset to have.*

Sasha related how, when she was diagnosed, people's lack of knowledge about and understanding of her illness may have contributed to some of the more negative reactions from and the interactions with others in her life: *I don't know...just...nobody knew it before. Nobody knew about lupus before. Nobody thought about it. Nobody understood what it was. Nobody knew what this disease was all about... I mean, I didn't look sick, you never look sick, you know. When you're reexperiencing a flare, the inflammation and the pain, the discomforts there [don't] really show unless you show the people... You develop a heightened*

sense of relationships now, because you're aware of things you can and cannot do and, because of your awareness of what you can and cannot do, you're no longer able to plan ahead... I stopped planning in advance. I stopped making promises. I became so aware that it was, it could be perceived by others, as my just bailing out or not following through or not...you know...keeping to the commitment I made.

5.2.3 The Social and the Psychological: Internalising Social Expectations

The hyper awareness of how others perceive Sasha, and the impact her illness has had on her relationships, is reflected in the difficult relationship she had with her primary supervisor. She attributed much of the division and conflict between herself and her primary supervisor to the impact her illness had on her ability to submit drafts timeously and to the lack of understanding of the illness itself on the part of her supervisor: *What I found as well was that, because I wasn't able to work on my thesis consistently and send in stuff regularly, I also created distance between myself and them... I always felt like my supervisor would be thinking, "Argh, she's just not doing her work" ...he was sympathetic, but I don't think he was empathetic and I don't think he took the time to actually get to know and think about it and even to accommodate me. But I think, also, he's just so caught up in his own world.*

Fears of prejudice and being perceived as incapable have made Sasha feel as though she cannot rely on others, particularly at her place of work: *But I think the people that don't really [understand], are not people I am close to, like my colleagues for example. I think some of them... „Ch ya, okay“, but they... I don't think they understand, you know... I cannot tell people I can't do this because I won't cope with it, because of my illness. So I won't use that (excuse), I won't say it. I would just do it, even if it kills me... I've had an experience where it has been used against me.* This complex interaction of misperception and prejudice has created an unsupportive academic and work environment for Sasha, which creates additional barriers for her.

Annah expressed similar fears of prejudice. Being active in the ministry and having her bishop sitting on her college board, Annah is fearful of accessing help with her studies: *I don't generally share my illnesses with people who are not in my inner circle. It may sound strange, but being a woman in ordained ministry is not without prejudice. The less ammunition people have to use against me, the happier I am. My college is unaware of my*

chronic illnesses, as my bishop sits on their board. He has been told, but I don't know that he remembers and I try not give him any reason to remember.

Additionally, Annah has also experienced a less than understanding reaction from others in her life: *When I was first diagnosed I tried to explain to my mother-in-law what was going on. I gave her a book explaining the symptoms. She got to the first paragraph, which spoke about chronic fatigue and said she clearly had this too because she also gets tired. I took the book away, said "Never mind mom", and never spoke to her about it again.*

In all these cases, the participant experiences negative reactions from significant others – supervisor, employer, mother-in-law – and to some extent internalises these reactions which, in turn, shape their responses to other people and social situations. Unsupportive social environments seem to stem from issues surrounding the perception of illness, particularly illnesses such as these that are not well known and have few observable manifestations. For the participants, accessing help is marred by negative perceptions, prejudice, misunderstandings and fear.

5.2.4 The Affective Dimensions: „Feeling“ Self and Society

These excerpts are not only an example of difficult and unsupportive relationships within the social context, but also provide a glimpse of the inner turmoil and psychological conflict that the participants endure. The interactional disability model delineates that psychological aspects in interaction with social and physiological factors contribute to disablement. Feelings of aloneness, guilt, fear, doubt and helplessness further hinder the affected person. Sasha's narrative is possibly the most poignant in this regard as she reflected on the times she was too ill to work and had to rest instead: *I felt terrible. I felt useless. I felt like I'm not doing my work... Lazy! I felt that a lot! All the time I kept thinking, "Oh my God, you're so lazy, you should be working, why aren't you working?" I still feel this way.*

Sasha has been deeply affected by the symptoms of her illness, not just on a physiological level, but on a psychological level too. She questions herself and questions the validity of her illness. This, in turn, affects how she treats herself, whether she allows herself rest and care or lambastes herself for not performing at the level that she expects of herself.

The psychological effect of illness for the participants seems to temper decisions around accessing help which, in turn, creates additional barriers. This is demonstrated in Vanessa's narrative. She seldom asks for help or tries to access support. She does not like people to see her when she is ill or „vulnerable“ and, in turn, will often isolate herself: *I find it to be very humiliating when I'm flared up or in any sort of pain. Initially, there was a lot of shame that I felt with the disease. I didn't want anyone to know. It took me a while before my extended family knew. I don't know why there was that shame (laughs). I don't know. I maybe felt I'd done something wrong which caused it, whether an actual physical thing or whether I (laughs) did something wrong to the universe, that sort of situation. But I was really ashamed. Now, I'm not. I'm fine with telling people, but when it comes to me actually experiencing pain I don't want anyone to see... I would never even have people come visit me. Sometimes, if I'm sick for a while, then they, you know...friends are concerned. I don't like it...[them] seeing me like that.*

5.2.5 The Interactional Model of Disability and Chronic Illnesses

When situating chronic illness within the wider disability debate, one can construe that the attitudes and perceptions of illness and disability held by society and by the affected person will impact on them psychologically. This is evidenced by the literature in chapter two and it is shown by the narrative extracts above that revolve around the internalisation of social expectations and the resultant stress and psychological turmoil it can create.

Although great strides have been made in the development of the interactional disability model, which can encompass the disability experiences of the chronically ill and recognise the connection between impairment and disability (Shakespeare, 2006; Shakespeare & Watson, 2001), society still has particular views of what a disability is and the course that illness should take; chronic illness does not always fit that picture (Wendell, 2001). This creates a conundrum for those who are chronically ill. Society, in general, has preconceived notions about how illness should „play out“.

[Y]oung and middle-aged people with chronic illnesses inhabit a category not easily understood or accepted. We are considered too young to be ill for the rest of our lives, yet we are not expecting cure or recovery. We cannot be granted the time-out that is normally granted to the acutely ill (or we were given it at first and have now used it

up, overused it), yet we seem to refuse to return to pre-illness life. We are not old enough to have finished making our contributions of productivity and/or caregiving; old people with chronic illnesses may be seen to be entitled to rest until they die. And we are not expected to die any time soon, so we are going to hang around being sick for a long while. (Wendell, 2001, p. 21)

Society has mostly accepted traditional disabilities and has made space for those who are affected. Those who are chronically ill are perpetually in limbo, neither on the edge of death, nor having any potential of returning to the pre-ill self. This „non-category“, neither well nor „disabled“ in the traditional sense, leaves the chronically ill isolated (Wendell, 2001). This in itself is disabling.

Clearly, disability is not a simple construct. Factors that contribute to disability cannot be viewed in isolation. Disability arises from a complex interaction between social, psychological and physiological aspects which are often reinforcing. This interplay is seen in the narratives shared by the participants. Obstacles and barriers in their lives stem from a myriad of interacting factors that shape their day to day lives.

5.3 Jarvis“ Learning Theory

Learning is an integral aspect of this study and thus, Jarvis“ learning theory is used as a lens in order to explore themes and patterns in the data. Jarvis“ learning theory purports that learning involves the whole person, in its entirety. A fundamentally human phenomenon, learning is a holistic process which is mediated through a dynamic interaction of the mind and body in relation to the world around us (Jarvis, 2005, 2009).

According to Jarvis (2009), disjuncture can be a catalyst for learning. Disjuncture, or a “sense of unknowing” (p.22), is responded to in a number of ways which can result in learning or non-learning. This disjuncture typically occurs when there is discord between ourselves and our world as we know it. With reference to this study, chronic illness creates disjuncture. In terms of Jarvis“ learning theory, the physical toll of chronic illness has the potential to disrupt previous ways of learning in a formal setting. In order to adapt to a new way of being, recognising this disjuncture and responding to it by acquiring knowledge and „closing the

gap“ between the known and unknown are critical to successfully moving forward in one’s learning (Jarvis, 2006, 2009, 2012).

Jarvis (2006, 2009, 2012) explains that our bodies function as our primary learning instrument. Bodies that are ill, or impaired in some way, impact on our motivation and ability to learn: “There is a dialectic relationship between us and the world and in some ways our body is that element through which this relationship is conducted” (2006, p. 38). Illness can impair how effectively our bodies process sensations and mediate the relationship with the external world: “[D]uring times of physical illness we are less likely to be motivated to indulge in concentrated studying, so that the state of our body affects our motivation to learn” (Jarvis, 2006, p. 39).

As primary learning instruments, ill bodies cannot function as effectively as healthy bodies. The excerpts from the narratives shared under the disability lens demonstrate how the physical symptoms of illness create barriers to learning. Pain, fatigue and memory problems are real obstacles to learning. Additionally, stressors associated with learning seem to have a negative backlash on the participants’ health. This provides a picture of a convoluted relationship between learning and the ill body. Essentially, due to chronic illness, the world that was known to the person has now been altered and a new way of being lies within the unknown. The response to this disjuncture can affect how that person moves forward.

According to Jarvis (2012), “[h]uman beings rarely act in a mindless and aimless manner” (p. 16). Motivation or intentionality drives us to act, whether it is to remove “the uncomfortableness of disjuncture...[or] satisfy our desires, hopes and aspirations and so on” (p.16). When disharmony is created between the individual and their world, either by change within the individual or change in the individual’s world, this creates disjuncture, which becomes a driving force or motivation for learning and change (Jarvis, 2006). On the other hand, disjuncture can result in non learning: a refusal (either on a subconscious or conscious level) to incorporate new knowledge and adjust accordingly.

5.3.1 Learning about Illness, the Body and the Self as a Learner

The participants have developed particular ways of managing their learning. The way they tackle their learning is intimately linked with their illness as it impacts on how much and how

long they are able to study. They make use of schedules, tools and techniques, as well as drawing on resources such as family or academic support in order to get through the necessary workload.

Demonstrated by the excerpts below, the participants express the necessity of being ahead of schedule in terms of their studies. They know that at any time their illness can flare, hindering progress. They tend to adopt strategies and tools such as setting smaller study-related goals, resting when needed, asking for help and employing technology. Additionally, the participants all seem to have sacrificed other aspects of their lives in order to have the energy to put into studying. Often, their social lives are put on hold in order for them to pursue their studies. Mostly, the participants manage their learning through managing their time and energy reserves.

Time or the lack of time is a significant theme that is threaded throughout all of the narratives. This speaks to the unpredictability of these types of illnesses and its impact on their progress. At any time the illness can flare up and incapacitate the person, derailing any plans they may have. Vanessa often spoke about not having the same amount of time that the average person has: *I have to put in the effort now. I have to start early. I have to start making it (studying) happen, because I can't.. I don't know where I would be...and the worst thing is being in hospital... I find that I don't have 24 hours in a day compared to the next person.* This sentiment was echoed by Josephine: *I'm very conscious, I need a head start in case something happens and I'm not being pessimistic, but realistic, because I know that things can take me out...* And in my own narrative: *Due to the erratic nature of the illness, I never knew what the next day would hold for me and so I was constantly pushing myself to do more, to be ahead, never knowing when a flare would take me down. This, of course, was a double-edged sword, as pushing myself would often lead to a flare up of the illness.*

Time is a critical issue which impacts on how learning is tackled in general. This translates into how the day is structured in order to create time for studying. Josephine structures her days in a way that allows for rest periods and possible setbacks. Additionally, she has learnt to listen to her body: *For the last two years I've definitely have given studying my top priority. I structure my day in that I do my housework first...so I aim to start studying at about 8:30am every day, latest 9 o'clock. Then, I would study until lunch time. I am very into a tight schedule you know, I don't miss meals and that, otherwise I'll feel faint... So I just*

have learnt, you know...with my body, if I push myself right through the day, I struggle to make dinner.

Similarly, Vanessa is acutely aware of her body and its needs. She understands that her health and stress levels impact on her ability to study and so works to keep herself as healthy and stress-free as possible. This may be through increasing her medication, eating healthily, removing herself from conflict or building up a reserve of „down-time“ for when she does become ill, and by being ahead in her studies. Over the years, just as Josephine has done so, Vanessa has become better acquainted with the nuances of her illness and, subsequently, has learnt her triggers, her strengths and weaknesses. This knowledge is utilised as part of a learning management strategy. In these ways some of the participants showed that they were expert learners of their own illness, of its impact on their bodies and their consequent bodily rhythms. They seem to be able (often through bitter experience) to have „tuned into“ their bodies very astutely and sensitively, in order to be able to manage them effectively as „learning instruments“. While the body as a learning instrument is damaged or ill, they have learnt and now know how and when to „play“ the instrument. For Sasha and I, we have not always been able to „manage“ the instrument optimally. It is a continuous struggle, but it is also a learning process which we are beginning to understand, evidenced by the achievements we have made thus far.

Vanessa, Josephine and Annah manage their learning by breaking their study load into smaller, manageable pieces. Vanessa reflected: *I break it down per module; not per semester, not per year, just per module... I feel I have to break up everything into bits and pieces and I can swallow it like that because I can't do it like the next student, so to speak.*

Annah is careful about not overloading herself with modules and tries to keep the workload at a manageable level. She also bases her choice of modules on whether they are exam based or assignment based. Josephine uses every tool available to her, from accessing support from her husband and from her college, the use of technology, time management, illness management and her relationship with God. Her learning management strategies do not create conflict for her and thus, this „freedom“ allows her to maximise the use of the strategies and tools available to her. Josephine has learnt what works for her. This may be attributed to the length of time that she has lived with rheumatoid arthritis. Experience has taught her what she can and cannot do and thus guides how she manages her studies, as well

as other aspects of her life. Her balanced approach is in contrast to some of the more harmful strategies adopted by the other participants.

5.3.2 Learning or Non-learning

Like the others, Sasha and I have had to prioritise studies over everything else, but we both tend to adopt techniques that are perhaps not as „forgiving“ in terms of „down time“ as the others. Sasha would switch tasks in her studying when one task became too cumbersome. This provided her the opportunity to move forward, even if incrementally, but inevitably there were days that she was just too ill to do anything and this caused her great strife: *On the days I couldn't write I would just read or reread stuff... On the days I was exhausted I couldn't read or write and I just had to sleep or stop doing whatever I was doing; those were the days that things really got to me. Then I would feel useless and stupid and lazy... There were times I [would] sit the whole day and be watching TV or sleeping and I thought, "How can you do this?", and then the next day I would be ridden with guilt.*

The issue of guilt and psychological lambasting is echoed by the excerpts from my own narrative. There is an element of non learning in the way Sasha and I push our bodies until they can take no more. It reflects a level of doubt in our own legitimacy as ill people who need rest. It also reveals an unhealthy learning management strategy.

Although the participants in this study have adopted and adapted a number of techniques and strategies to allow them to move forward in their studies, they also demonstrate a reluctance to use other strategies which, on the surface, seem to be logical and useful choices. This seems to stem from issues surrounding identity and perception management, but can be tied to non learning and denial. Most of the participants talk about strategies such as enlisting additional help, breaking up their studying into smaller manageable chunks and resting when needed, but these strategies are not always used. The Dialogical Self Theory, which is discussed next, sheds more light on this reluctance to use these particular strategies. The following excerpts touch on the non use of learning management strategies.

The delegation of responsibilities and accessing help is another tool that the participants mention in their management of their learning but, although they speak about it in theory, in practice, they seldom use it. Annah talks about delegating responsibilities which allows her

more time to dedicate to her studies, but this is not easy for her, as the role of mother, wife and her work in the ministry are demanding and important to her: *Added to the studying, which saps my strength, I have a family who need my attention. I'm in ministry, which is time consuming, and physically and emotionally draining.*

Although Sasha recognises that she cannot „do it all“, at the same time she does not want to ask for help. There is a deep-seated need to have some kind of control: *I still have great difficulty coming to terms with how little control I have with the effect the chronic fatigue has. I still push myself.*

As in the case of Sasha, Vanessa also struggles to ask for help or try to access support. In particular, Vanessa is reluctant to access help from her university: *When I look at myself and my future, I know that I am going to have to do everything on my own. I know it's just going to be me... Every year I say I'm going to make arrangements with the university, so then, in the event that I cannot write, I can type it or somebody can...I don't know...something; but every year I don't do it and I always end up writing and it's a very painful experience... I guess also, because you don't really want to be like a special needs person (snorts with laughter) and if it were to happen I'm not just a normal person coming to write this exam.*

Annah, too, has not tried to access help at her college, but her reasons stem from fear of a possible prejudicial response from her college. Unlike Annah and Vanessa, Josephine had no qualms accessing help from her college when she started to struggle with the workload. The college supported Josephine's choice to drop a subject and only focus on one subject per semester. With this support, Josephine has been able to slow down and enjoy her studies more.

All the participants have experienced disjuncture through chronic illness. Depending on the individual, the response to that disjuncture manifests in different ways. Learning occurs on many levels and in varying contexts. Because of their illness, most of the participants seem to show high levels of reflexivity, reflecting on how they learn and how to manage themselves and their bodies as learners. The idea of the body as a learning medium or instrument has a particular importance in relation to chronic illness. The body, in many ways, also acts as a „teacher“. In order to be a successful learner, one has to learn to listen to one's body and respect its needs. This „listening“ or „ignoring“ of the body ultimately affects how successful

the person is in their learning within a formal context. Learning occurs in many aspects of life. In some areas of the participants' lives, they have learnt to adapt and change their strategies to further their goals, but in other areas it seems that non learning becomes an issue, particularly if changing the way of doing things has a negative psychological impact. This seems to be the case, particularly when there is a threat to the person's identity. The issue of identity is addressed in the following section.

5.4 The Dialogical Self Theory

According to the Dialogical Self Theory, a person has many selves or I-positions. These I-positions and social selves are multiple and not necessarily congruent with one another. The self which is most salient is context-dependent and is influenced by how important that I-position is to the person in question. These many I-positions develop internally as a sense of self, and externally, as we interact with others and our environment. A person not only positions him/herself, but is positioned by society and their interactions with others. Society and our interactions with it create our social selves such as I-as-mother, I-as-caregiver, I-as-student, I-as-wife, I-as-adult and so on (Bertau & Gonçalves, 2007; Hermans, 2001, 2003, 2013, 2015; Hermans & Hermans-Konopka, 2010a; Thomson, 2006).

Ultimately, illness creates discord and, in this, the construction and maintenance of one's identity is shaped. The following excerpts demonstrate just some of the multitude of I-positions that are reflected within the narratives. These I-positions jostle for dominance, create conflict or work together in coalition, reinforcing I-positions to support the envisioned self. Additionally, I-positions can work together to reinforce negative perceptions of the self in an act of criticism or self punishment. An extract from my own narrative demonstrates this: *But as time moved on and I saw the others so far ahead of me, I began to feel panicked. I was so slow. Everything took me twice the amount of time it took the other students.*

Several self-positions are evident in the above extract such as I-as-left-behind, I-as-panicking, I-as-slow. These various self-positions form a constellation of mutually reinforcing negative positions, what Hermans terms an „alliance“ within the self: “[T]he positioning process can lead to monologue in which one voice is overly dominant and the other silenced, with the implication that co-constructive learning is hampered or even blocked” (Hermans, 2012, p. 12).

Within the mini-society of the self, the I-as-sick position may become dominant and reinforced by positions such as I-as-slow, I-as-depressed, I-as-unable. This, coupled with external positions ascribed to the self, lupus-patient, disabled, etcetera, may lead to a dominant monologic voice in the self, constraining dialogic engagement with other possibilities of the self.

Sasha's negative relationship with her illness and the impact it has had on her identity are particularly demonstrative of negative I-positions that work in coalition as a source of self-criticism and an unwillingness to accept her illness as a part of who she is: *2011, 2012...actually those two years, [were] really a matter of coming to terms with having this disease and learning to adapt to it and I found that very difficult because it prevented me from being who I was. It prevented me from doing things that I did before. It prevented me from functioning in the way I functioned previously and that was the hardest part; dealing with that.*

Sasha's language demonstrates tension and conflict. There is a striking emphasis on a specific, conflict-ridden transition ("2011, 2012"). The passage shows a disjuncture in time between a healthy and functional past time and an unhealthy dysfunctional present. „Illness“ is objectified as „other“: „it“. This „other“ is a threat and an inhibition to the preferred self ("prevented me from being who I was"). Note, also how the triple repetition of "prevented me" emphasises the inhibiting power of the „illness as other“. This also creates a break between the past self who is associated with agency, self-fulfilment, functionality, and the present ill self. This conflict among self-positions is within the arena of the self and creates a type of paralysis or inaction within the self ("prevented me"), as well as an experience of acute stress ("very difficult"; "hardest part").

5.4.1 Acceptance, Denial and the Self

The participants' sense of self seems to be regularly challenged by their illnesses. Illness impacts on their ability to function in a way that supports their chosen I-positions and social selves which, in turn, creates a state of disharmony. This disharmony and various I-positions, jostling for dominance, may both express and stem from the acceptance or denial of illness. The theme of acceptance or denial of illness runs through the narratives. Mostly, there seems to be a natural progression from denial when first diagnosed, to a point of acceptance gained

over time whilst living with the illness. However, it seems that, due to the hidden nature of these types of illnesses, their social acceptability and the characteristic intermittent spells of good and bad health, the state of complete acceptance or complete denial is not absolute. To further complicate this matter, the unstable nature of autoimmune illness, with its periods of good health and bad, makes difficult the incorporation of the self, I-as-sick, as a permanent aspect of identity. The narratives reveal a convoluted relationship between how the participants view themselves, their illness and how they think others perceive their illness.

Although Sasha is working towards accepting her illness and the limitations it places on her, she struggles with feelings of guilt and incompetency when her body fails to meet her standards. Her perception of herself as a strong, competent activist, teacher, academic, mother and wife does not fit with her ill-self. These I-positions are in conflict with each other. This is demonstrated by her reluctance to make adjustments to her workload or access help from others. She continues to push as hard as ever, but now is more vulnerable to setbacks in her health. She continues to feel that the diagnosis was a mistake and this denial affects how she feels about herself when she cannot keep up with her work or needs to rest more often: *That's how I felt when I couldn't work at my thesis. I felt like I was wasting all this time. I felt like I was lazy, like I was not competent.* For example, Sasha's I-position of I-as-sick contradicts her I-position, I-as-strong. An inevitable conflict arises, as the two positions do not fit. Sasha engages in strong self-criticism by occupying a number of recriminatory positions to criticise herself: I-as-lazy, I-as-guilty, I-as-exhausted.

In contrast, throughout Josephine's narrative there is a sense of peace and complete acceptance of her illness. Josephine has been ill for most of her life. She, too, struggled with denial for many years. A turning point for her was when she gave meaning to her illness and associated it with God's plan for her: *I would say, initially I went through [a] terrible period of denial. I could not accept it. Nothing good would come out of this for seven years. At that point, when I came back to the Lord in Pretoria, I started little by little to see, "Hang on a minute, God is using this in my life" He (God) really is the reason that I have not remained a victim of the disease, but I feel that I have victory in my life.*

Through this acceptance, Josephine has adapted her lifestyle to accommodate and make room for her illness. The jobs that she has had have always been jobs that she could do from home or even from her bed if needed. She is also acutely aware of what her body needs and has

learnt to listen to it by sticking to a structured day that allows her to work, but also to rest: *Although this disease has taken a lot from me, I have done a lot. I've been, you know, hardly idle, [but] ...I am much better [off listening] to my body.*

Josephine's narrative conveys very little guilt. She feels that she is living her life with purpose and accepts her illness as a part of her journey in life in the service of God. There is cohesion of her various I-positions under the premise that this is God's purpose for her. She is able to incorporate her I-position, I-as-ill, with I-as-God's servant.

5.4.2 Motivation, Learning and the Confirmation of the Self

The Dialogical Self theory purports that motivation and identity are interlinked. As briefly discussed in chapter two, Batory (2010) proposes that six identity motives; self-esteem, efficacy, continuity, distinctiveness, belonging and meaning, play an important role in the shaping of identity. These identity motives are reflected in the narratives shared by the participants.

Sasha's motivation to study stemmed from her passion for research and advocacy. Completing her PhD played an important role in supporting her sense of self as a strong female academic and activist who can „do it all“. This goes some way to explain the terrible guilt and sense of uselessness she felt each time she could not study. It would seem all the above identity motives are plausible explanations behind her perseverance: *I was really excited and passionate about this research and this work. I'm very passionate about my teaching. For me, what links to my teaching is my activism... I'm so passionate about issues of oppression, both in terms of my own and our general experiences in South Africa, but also because (pause) maybe I'm just (pause) that kind of person who wants to, can't not do something about the inequities and inequalities and injustices we see around us... I think I'm an activist first and academic after that, because that's always been my passion. It's what motivated me.*

Josephine's motivation is clear throughout her narrative. Josephine feels that God wants her to study theology in order for her to better serve Him. This has been a powerful motivator; she is striving for her purpose in life. Studying was not something that Josephine had even thought of doing but, as Josephine explains it, God guided her to this choice: *Yes, I...it was*

never on my radar screen to study. It hadn't, I hadn't even had one thought about it (studying)... George and... all of a sudden, out of the blue, we just discussed it and we thought, you know, we feel this is exactly what God wants me to do.

Vanessa spoke about needing her degree in order to increase her earning potential and ultimately improve her life. Studying is her ticket to financial freedom and independence, which she deeply values. Being deeply unhappy, living with her parents and having little control over her life, studying has become an important tool in order for her to access the life she has envisioned for herself. Vanessa's narrative also demonstrated a deep seated need to be able to accomplish her goals, despite having lupus. In her quest to be independent, strong and in control of her life, it is important to her that she is not „defeated“ or have limits placed on her by her illness: *To me, it's like I have to do this. It's the only way I'm going to survive. Then, it's not that it becomes easier, but it's that I'm more determined and I know that I have to work harder. I know that I have to put in more than the next person. I want it so badly. I don't want lupus to be the reason why I don't... I can't get it (her degree).*

Motives such as efficacy, continuity and meaning seem to form, at least in part, a fitting explanation of what keeps driving Vanessa forward in her studies, despite the odds stacked against her.

Annah's motivation first stemmed from the need to study something that she could make a career out of, which would not be as physically demanding as her current work. She decided that psychology would be a good career option for her that would allow her some flexibility with regards to the times she worked and would not require her to be on her feet. This motivation, though, changed over time. Annah felt a strong calling to work in the Christian ministry and so decided to change from studying psychology to theology: *Yes, deciding to study psychology was based on my physical limitations. The switch to theology was because of a calling. Not sure what's to come after that... I'll wait for God to lead the way.* Pursuing and fulfilling her purpose in life seems to be the dominant motivator which urges her on regardless of the difficulties she faces.

Motivation, in the context of this study, varies from person to person. These motivations seem to be based on how the participants view themselves, their situation and their purpose in life. Identity and motivation are closely tied and this is reflected in the stories shared by the

participants. Despite the difficulties of living with chronic illness, the participants continue with their studies. Learning, not only helps the participants reach their explicit learning goals, but also confirms and supports their chosen I-positions.

5.4.3 Relationships, Illness and Disclosures

Identity is shaped, not only internally but externally, as we interact with others. Thus, the relationships we form and how we interact with others are integral to our identity formation. Illness can potentially impact on relationship dynamics and subsequently shapes the self. The narratives shared by the participants reveal how illness changed many of their relationships, personally, socially and professionally. On a physical level, illness limits energy and thus impacts on how the affected person will interact with others. Developing and maintaining relationships requires commitment, maintenance and energy. Illness potentially limits socialising and relationship building. Most of the participants voiced concerns that their friends may not understand that they cannot socialise the way they used to and they expressed fears that they may not have many friends once they have completed their studies. The participants also shared how others have had to step in and help, during times of their limited functional capacity in their respective roles within the context of their personal and professional lives.

For some of the participants, illness has strengthened their relationships as they have drawn on the support of significant others, friends and colleagues, shown here as Sasha reflects on the support she received from her work colleague and her primary supervisor: *Thank God I had Mary with me. Mary was amazing, coz when I couldn't manage and I couldn't cope, Mary was there and I was co-teaching with her, so it took off, took the stress off me... My supervisor, Thandi was amazing and she called me and spoke to me and told me that nothing is more important than my health; not the thesis, not work, not anything else.* Josephine reflects here on the support her husband has provided to her over the years: *My husband has been fantastic to me over the years. You know, not many people would marry somebody with this disease. He's always been able to see beyond the disease, which was really important... George has always just treated me as though I was absolutely normal, which really has helped me, you know. I mean, he just thinks I look beautiful when I know I look shocking.*

Unfortunately, in other relationships, this has not been the case. This seems to be tied to whether the participant has revealed their illness and whether those whom the participant has revealed to, truly understand and accept what the illness entails and its range of effects. Vanessa explains some of the difficulties she has at work: *My boss knows, and she knows that there will be times where she won't be able to see it, but she's not very understanding. She's not the type of person who'll say "Oh, go home coz you aren't feeling well, you aren't looking well", whatever.* Sasha's experience with her other supervisor was the polar opposite of her experiences with Thandi: *Yes, he was sympathetic, but I don't think he was empathetic and I don't think he took the time to actually get to know and think about it (her illness) and even to accommodate me.* Both of the above extracts demonstrate experiences of disclosure, but a less than desirable response to that disclosure. Disclosing illness can be useful, as it has the potential to rally support and understanding but, disclosure can lead to disbelief, prejudice and negative interactions between the affected person and others.

Non-disclosure can function as a form of perception management that helps preserve a person's sense of self, as demonstrated by Vanessa's reluctance to disclose to her university which serves to protect her sense of self as „normal“, independent and self-sufficient. It may also help to protect a person against negative perceptions and interactions from others but, ultimately, non-disclosure stands in the way of accessing help and understanding from others. As was posited earlier, there needs to be a fit between a person's I-positions and social selves. Thus, some of the motivations behind disclosure or non-disclosure can be understood within the context of the Dialogical Self Theory. The extracts below illustrate this point.

As discussed earlier in chapter two, being ill and „needy“ has a socially devalued position. This, in turn, impacts on whether an „ill-self“ will be incorporated into one's identity. Someone who views themselves to be competent, in control and actively making a valuable contribution to society, would most likely resist being positioned as ill or disabled due to the associated negative connotations and incongruence with the envisioned self. This may go some way in explaining why the participants struggle with acceptance of their illness and/or disclosing their illness to others.

Disclosure and non-disclosure are mediated by help-seeking behaviour, coping techniques, perception management and, ultimately, one's identity. Additionally, fear of prejudice and possible negative perceptions of illness also impact on disclosure or non-disclosure decisions.

Although the participants spoke about resting and accessing help as tools in the management of their learning and other aspects of their day to day lives, some also spoke about experiencing guilt when trying to rest and often not delegating responsibilities to ease their workload (studying, work and home life). Their perception of themselves and their need to manage the way others perceive them seem to play a key role in choices made around disclosing to others and accessing help as ways to manage.

This is evident in Sasha's narrative, where she spoke about learning to delegate and accepting that she cannot „do it all“ but, within that same narrative, she expressed her reluctance to drop any of her responsibilities: *If I can't get to something today, I will get to it tomorrow, but I still won't say "Can you do it?".* Additionally, Sasha also expressed fear of others viewing her as incapable, weak and sick: *I feel I have to do it because, if I say I can't do it because of my illness, it is going to work against me. I'm going to feel that people will feel, "Oh, let's not give it to her coz she can't do it she's not well". So, I feel like even when I can legitimately say that I can't do this, because I won't cope with it because of my illness, I feel like that it is an excuse and I cannot use it... I think you become so conscious of the fact that you can't do things because of the illness you don't want people to see you in that way. You don't want people to see you as not being able to do things because you have an illness.*

The above excerpt demonstrates Sasha's attempts at perception management. Although damaging in many ways, it serves to protect her envisioned self. This protective action is congruent with Sasha's I-positions as a strong woman who can work, study and fulfil all of her family obligations. It also shows how the external other becomes an "other-in-the-self". We see this in phrases such as, *"I'm going to feel that people will feel... „she's not well“"* and *"you don't want people to see you in that way"*. Her perception of what other people think (external other: „she's not well“) becomes a self-perception (internal other: „I'm not well“) that she denies (*"I feel like that is an excuse and I cannot use it"*). This protective action results in a deep conflict and continuing unresolved struggle within the self.

Vanessa sees herself as very independent, which is evident in her narrative. She often talked about being on her own and having no one to rely on except herself. She also expressed reservations about accessing help from the university with regard to her studies for fear of being seen as „special“ and unable to manage on her own. Vanessa demonstrates a reluctance

to disclose. An example from Vanessa's narrative, used under the learning theory lens, illustrates this. She needs to maintain the I-positions integral to her personal self (I-as-independent/self-sufficient). Her non-disclosure to her university and lack of help-seeking is in line with the I-positions most important to her. It is also a denial of the external other's perception of her as having "*special needs*" and so not being "*normal*".

Annah expressed similar concerns, but perhaps these concerns were more to do with fear of prejudice than of being seen as someone who needs additional help to cope. Her relationship with the bishop, who sits on the board of her college, creates additional barriers as she internalises the „other“. The self takes on positions that come from outside which, in turn, become the „other-in-the-self“. Annah internalises the „other“ of the bishop, he-as-disapproving, he-as-unsupportive. This internalised, criticising „other“ heightens Annah's fear of prejudice which, in turn, „validates“ her choice not to disclose.

Josephine seems to be the most comfortable with accessing help, resting when needed and utilising other tools to manage her learning as effectively as possible. This may be due to the fact that using these techniques, tools and resources do not threaten who she believes she is and her purpose in life. Disclosure seems to be the least problematic for Josephine. Her position I-as-sick, is part of the broader alliance of selves under the umbrella I-as-God's servant.

5.4.4 Emotions: The Temporary Self

Pervasive emotions are evident throughout the narratives. As discussed earlier in chapter two, Hermans understands the crucial role of emotions in the positioning of the self (Hermans & Hermans-Konopka, 2010a, 2010b). He sees emotions as „temporary self positions“ that can have a powerful influence on how one perceives oneself and others. There are powerful emotions in all the narratives, ranging from anger, despair, and denial to acceptance, relief and hope. For example, the powerful emotion of fear is evident in the narrative extracts above, particularly fear of other's perceptions: Sasha's fear of being seen as ill; Vanessa's fear of being classified as „special needs“ and dependent and Annah's fear of compounding prejudice against her as a woman. This emotion leads to the denial or rejection of certain self-positions which Josephine, in her position of I-as-accepting my illness, can accommodate. Hermans and Hermans-Konopka (2010b) state:

[O]penness to a new “I” position depends on the organization of the repertoire. We suppose that feelings can help the self be more open to new “I” positions (e.g., love), whereas other feelings (e.g., fear) will close the self for the possibility of introducing new positions. (p. 98)

Emotions have the potential to change self-experiences and thus can facilitate self-change or reorganisation of the self. Those who experience positive emotions will be more open to new I-positions and new ways of interacting with their environment than those who experience negative emotions. This is particularly relevant to the study at hand, where most of the participants are plagued by feelings of fear, guilt and loneliness and thus are less able to cope with experiences of illness and their self as an ill person (Hermans & Hermans-Konopka, 2010b).

It can be construed that a person’s I-positions will influence their projection of their identity, perception management and management of their relationships, learning and day to day activities. Management strategies that fit with a person’s I-positions and social selves are more likely to be embraced and utilised. If these tools, resources and techniques are in conflict with a person’s I-positions and social selves, that person is far more likely to abandon them in favour of other management strategies which maintain and support their perceived selves, even if they are not the most effective. Instrumentally, these factors influence disclosures and non-disclosures and, subsequently, the affected person’s ability to cope.

5.5 Conclusion

The rich data that emerged from the narratives revealed particular themes and patterns that I examined using the interactional disability model, Jarvis’s learning theory and the Dialogical Self Theory as theoretical lenses. In turn, I contextualised and illuminated aspects such as illness management, learning management, relationships, disclosures and identity construction through the use of the above theoretical frameworks. In sum, one can construe from the themes that the experiences of adult learners with hidden disabilities in the higher education context is multifaceted, complex and interactional. Their intrinsic and extrinsic experiences of the world are mediated by illness, which creates numerous obstacles and barriers in terms of their learning and living in general, as well as possibilities for new „alliances“ of positions within the self.

CHAPTER 6: CONCLUSION

6.1 Introduction

This concluding chapter aims to synthesise and integrate the discussions and findings that emerged from this study. I examine the research questions in relation to the study's findings and the relevant literature. Additionally, I discuss the implications, insights and recommendations stemming from the research and an overview of the study's limitations. Lastly, I examine areas for possible future research.

Chronic illness, and in particular autoimmune illnesses, has the potential to disrupt and impair day to day living. This carries over into the higher learning context. Pain, fatigue and a multitude of other symptoms contribute to the disablement of those living with a chronic illness. Not only do the physical symptoms of chronic illness impact on the learning experience, the psychological aspects of illness and disability play their role too. The hidden nature of these types of illnesses contributes to a myriad of complex psychosocial interactions that further disable the person in question. Adult learners already face a number of hurdles in learning, in particular, energy-demanding and time-consuming adult responsibilities which, consequently, detract from time and energy required for learning. This conundrum is exacerbated by chronic illness.

As identified in chapter one and expounded upon in the literature review, there is a need for further research, particularly in the fields of adult education and disability (Clark, 2006) and chronic illness in the higher education context (Jung, 2002). Additionally, there is a lacuna in the literature that looks specifically at adult learners with chronic illnesses as „hidden“ disabilities in the South African higher education context. Higher education institutions should be invested in the inclusion and successful education of those with disabilities. This includes those who are chronically ill. In order to ensure a successful learning experience for these students, a better understanding of this population is required.

Therefore, the purpose of this study was to gain insight into the lives of chronically ill adult students as they navigate their way through higher education. Specifically, the objectives of this study were: to understand the impact of these students' illnesses on their learning and day to day lives; to identify the techniques that these students use to cope with and manage their

learning; and to investigate the ways in which these students understand and project their identities.

The experiences and challenges of adult learners who are chronically ill are multifaceted and complex. Chronic illness impacts on each and every aspect of life. There is an intricate interplay between illness, learning, identity, and the roles and responsibilities associated with adulthood. How well learners cope with this is dependent on a number of criteria such as managing identity, the assimilation of illness into that identity and the utilisation and strength of their respective support systems.

As an exploratory study, this research set out to garner insight into the experiences and challenges of chronically ill adult learners in the higher education context. A narrative approach, set within an interpretive paradigm, was used to elicit descriptive narratives from the participants, who ultimately are the experts on their own lives. Through in-depth interviews, participants shared their stories. The data were analysed, whereby themes and patterns were identified. These findings are discussed in relation to the research questions and the relevant literature. This study endeavoured to answer several research questions that would contribute to the understanding of chronically ill learners. The research question and subquestions are as follows:

6.2 Research Questions

What are the experiences and challenges faced by adult learners with „hidden“ disabilities in the higher education context?

1. How does living with a chronic illness impact on these students' ability to learn and succeed in their education?
2. What coping techniques do these students use to manage their learning experiences?
3. How do these students understand and project their identities?

These research questions are examined in relation to the findings and relevant literature.

6.3 Research Questions and Findings

What are the experiences and challenges faced by adult learners with „hidden“ disabilities in the higher education context?

1. How does living with a chronic illness impact on these students“ ability to learn and succeed in their education?

All of the participants have experienced or continue to experience difficulties in their learning due to their illnesses. These difficulties range from physical obstacles, stemming from their bodies and/or external surroundings, to emotional and psychosocial barriers. Fatigue, pain and concentration issues are major contributing factors to difficulties experienced in their learning. The psychological impact and perception of illness (both their own and that of others) mediate their help-seeking and influence relationships and support structures, which exacerbates their difficulties. The findings in this study associated with adult learners with „hidden“ disabilities in higher education, echo the literature discussed in chapter two, which focused on the impact of chronic illnesses or „hidden“ disabilities on people both within and outside of the education context (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Olney & Brockelman, 2003; Royster & Marshall, 2008; Shiu, 2001; Valeras, 2010; Wendell, 2001).

Illness circumscribes how learning is approached and impacts on the length of time it takes to complete one“s education. All the participants have taken longer than the average student to pass each year of study.

Sasha: When my lupus started it just (pause), you know, impacted so significantly on my PhD, which took me much longer than I anticipated and I...you know, there were important times when I even questioned whether I was even going to get to the end of it.

Not only is this demoralising, it also extends the amount of time that the student is under „learning“ stress. Stress and illness, particularly in autoimmune illnesses, are inextricably linked and thus the more stress the person is under the more ill the person becomes which, in

turn, creates a vicious, compounding cycle (Davis, 2005). The participants often spoke of the extreme toll that „learning“ stress has on them and their health.

Josephine: If I have bad stress, the next day I"m in bed for the day. I can"t function. I know I"m willingly putting myself under stress to study... I [want to] keep it as compact and the time period as short as possible so as not to prolong the stress.

The participants have had to establish learning approaches that are cognisant of their illnesses. There is a precarious balancing act that each of the participants engage in whereby they try to juggle studying, other adult responsibilities and rest in such a way that they can accomplish at least some of their goals without pushing their bodies over the edge. This is a learning process whereby the participants draw upon their own resources, time management, knowledge of their bodies and other coping strategies such as drawing upon their support systems. Although the interplay of illness and learning has created numerous difficulties and barriers, the participants do display tenacity and resilience. This mirrors literature on adult learners in higher education, which ascribes attributes such as life skills, experience and knowledge to maturity (Howell, 2004; McGivney, 2004; Richardson & King, 1998). Perhaps, being mature adults provides them with additional coping skills which allow them to study whilst being ill; essentially to persevere. However, despite these positive attributes, their persistence is often to the detriment of their health.

This is in keeping with the ideas shared by Howell (2006), who argued that students with disabilities often engage in “self-injurious behaviour” (p. 175) in order to keep up with their studies. In this study, the participants“ narratives provide further insight into the motives behind this “self-injurious behaviour”. On the one hand, engaging in this “self-injurious behaviour” is simply to „keep up“ with their studies, but on the other, on a deeper level, it seems that the more in line their study goals are with their perceived identities, the more likely they are to persist. Studying, for the participants, helps manage and preserve the „self“ and moves them towards their life goals. For example, Josephine“s theology studies fits with her perception of herself as I-as-God“s-servant, Vanessa“s goal to increase her earning potential by getting her law degree, fits her I-position, I-as-independent. Sasha“s goal to contribute to academia and her activism through her PhD fits her perception of herself as I-as-educator/activist. For each of them, studying plays an important role in helping them maintain their I-positions and meet their life goals. This contributes to their successes in their

learning, but one needs to be mindful that these successes are often at the cost of their health and social relationships.

2. What coping techniques do these students use to manage their learning experiences?

The narratives reveal a variety of coping techniques utilised by the participants in order to manage their learning experiences. Time management, and specifically being ahead of time, is a common theme throughout the narratives.

Vanessa: I find that I don't have 24 hours in a day compared to the next person.

Josephine: I'm very conscious; I need a head start in case something happens.

Practical strategies, such as switching study related tasks, when one task becomes too cumbersome, to another task which may not be as mentally or physically demanding, as well as using technology to lessen the mechanical handling of books, which can be difficult due to painful joints, are also adopted by some of the participants. Some of them have established study routines, with particular focus on structuring their day around rest periods and meals. Their focus and understanding of their bodies as important learning instruments allow them to make space for their illness which, in turn, allows them to be more effective when it comes down to scheduled studying.

Josephine: I am much better [off listening] to my body

The participants also break their workload into smaller pieces. This could be, either by breaking the actual work into smaller chunks to make it more manageable and prevent a sense of being overwhelmed, and/or slowing down the entire process by taking fewer modules and stretching out the degree or diploma over a longer time period. Additionally, studying via correspondence seems to be the preferred mode of learning, not only because of work responsibilities, but also its flexibility in terms of time and being able to study at home, „sick in bed“, if need be.

Vanessa: *I break it down per module; not per semester, not per year, just per module... I feel I have to break up everything into bits and pieces and I can swallow it like that because I can't do it like the next student, so to speak.*

Managing energy reserves is also a common technique. The participants often sacrifice social activities and engagement with friends in order to have energy for studying. Drawing upon the support of family, friends and colleagues is a more common strategy than trying to access support from their respective tertiary institutions. The reasons for this include both psychological aspects and internalised social expectations. Disclosure or non-disclosure, as a tool to access support, is marred by complex psychosocial and identity aspects shaping this behaviour. This ultimately circumscribes which tools are utilised. Examples, such as Annah's fear of prejudice, which prevented her from disclosing her illness to her college, and Vanessa's reluctance over asking her university for examination assistance due to fears of being seen as "*special needs*", are of non-disclosure choices that are convoluted by psychosocial and identity aspects. This is in keeping with the literature in chapter two, that evidenced that fear of social embarrassment and stigmatisation delineates disclosures and help-seeking behaviour (Hunt & Eisenberg, 2010; Kulkarni, 2012; Möller-Leimkühler, 2002; Oliver et al., 2005; Rickwood et al., 2005; Trammell et al., 2007).

The above mentioned coping techniques adopted by the participants in order to manage their learning, particularly those that require help from others, are not simply chosen. It seems that the participants have had to carefully consider the consequences of utilising a particular coping technique. Their behaviour implies decision making based on a perceived cost to benefit ratio. Essentially, they consider how much something is going to help or harm them on a physical, psychological and/or social level? This complex decision making and utilisation of coping techniques is echoed in the literature concerning help-seeking behaviour and disclosures (Cornally & McCarthy, 2011; Hunt & Eisenberg, 2010; Karabenick, 2003; Kitsantas & Chow, 2007; Koydemir-Özden & Erel, 2010; Kulkarni, 2012; Möller-Leimkühler, 2002; Oliver et al., 2005; Olney & Brockelman, 2003; Rickwood et al., 2005; Roussel et al., 2011; Trammell et al., 2007). Help-seeking behaviour, disclosure and non-disclosure and perception management are closely linked (Davis, 2005; Fitzgerald & Paterson, 1995; Jung, 2002; Olney & Brockelman, 2003; Valeras, 2010). Referring back to Vanessa's example, it shows that her desire to have others perceive her as highly independent results in her hesitancy to disclose her illness and ask for help. Linked to disclosures, help-

seeking and perception management is how the participants understand and project their identities.

3. How do these students understand and project their identities?

The participants' understanding and projection of their identities range on a continuum of complete acceptance and incorporation of illness into their identities to denial and separation of the self from their respective illnesses. The latter has created psychological and emotional difficulties for the participants. Acceptance and incorporation of illness also varies, depending on the context, stage and fluctuations of the illness itself. The self is inherently complex and is influenced by a multitude of factors. Illness impacts on all facets of life and, in turn, plays an important role in the formation of identity.

Identity is dynamic. As we interact with others and our world we are influenced and shaped. Thus, illness that circumscribes these interactions ultimately influences the shaping of our own identities. Furthermore, the psychological consequences of illness, which influence how we feel about ourselves, also affect our identity. Those participants who had a complete disconnect between themselves and their illness had the most difficulty in coping, as their perceived self did not fit with their ill self. This was particularly evident in Sasha's unrelenting lambasting and self-criticism throughout her narrative. The participants who have incorporated illness as a core aspect of who they are are able to do so because they amalgamate their self and illness into a whole that supports their chosen identity. Josephine is a prime example of this, as being ill has become an important part of her role as God's servant. As discussed above, this acceptance of an ill identity spills over into how learning is managed. Josephine's acceptance of an ill identity allows her to disclose to her college and to access help, as it does not threaten her identity.

For some of the participants, even though they confirmed that their illnesses were indeed disabling, they are reluctant to embrace an ill/disabled identity, as it does not fit with their perceived selves. They do not want to project themselves as „abnormal“, „weak“ or „incapable“. Not only does this stem from a disconnect between their preferred self and an ill self, it also seems to stem, in part, from societal perceptions and expectations of chronic illness and disability. As Jung (2002), Wendall (2001) and Davis (2005) point out; society has particular expectations of how illness should „play out“ (such as length of time „being

sick“ and re-assimilation back into society as a contributing member) and what disability looks like. Chronic illness often does not fit these expectations, making it difficult for those who are chronically ill to incorporate illness into their identity and to project that identity. As demonstrated by this study, this reluctance to embrace an ill identity has ramifications in terms of self-perception, relationships, learning strategies and illness management.

6.4 Implications and Recommendations

Research on adult learners with disabilities, within the adult education research, is sparse (Clark, 2006). Additionally, in the South African context, it has been identified that knowledge about the experiences of adult learners with disabilities is limited and further research is required (Rule & Modipa, 2011).

This population of chronically ill mature students has largely been neglected in terms of research and policy implementation. As discussed in chapter two, there is a general lack of knowledge about these types of chronic illnesses and how they affect the person in question. This study has endeavoured, at least in part, to bring to light some of the issues faced by these students.

A number of South African legislative policies for the integration and assistance of students with disabilities in the higher education context are in place, but, as the *White Paper for Post-School Education and Training* (DHET, 2013) points out, “[d]espite this strong legislative and policy framework for addressing disability in the education sector, access and support for people with disabilities remains limited” (p. 45). South African disability legislation recognises that disability is diverse and can manifest from a myriad of sources. This requires a diversified response from higher education institutions in terms of disability accommodation. This, ultimately impacts on policies and procedures within the higher education institution itself.

Most higher education institutions have disability policies that can accommodate those who are disabled by chronic illness. However, at a practical level, policies and procedures to access help are not designed for the chronically ill, but rather are based on the „traditional“ view of stable, physical disabilities. This results in difficulties for chronically ill learners in accessing accommodation. Additionally, the resources available to those with disabilities are

not necessarily helpful to those who are chronically ill. This means that how one accesses disability resources and what those resources are is in need of review and possibly, redress. Criteria for bursaries, scholarships and awards for academic excellence also need to be reviewed, for example, at UKZN, in order to be awarded a degree cum laude or summa cum laude, the student needs to finish their degree within a particular time period, regardless of whether the student has a disability or not. This policy excludes students with disabilities, who have excelled despite the odds, from being recognised academically due to taking longer than the average student.

In order to assist these students, further research is required. A better understanding of the push and pull factors that these students face, the barriers and accessibility problems they experience, and the accommodation needed is essential. Educational campaigns around chronic illness and services available to those who are chronically ill are needed to improve the visibility and awareness of this „hidden“ population. Students with chronic illnesses cannot access help if they are unaware that there are resources and accommodation that could potentially assist them.

6.5 Insights - Learning from the Research Process: A Dialogical Perspective

As I began this journey, I had certain hopes that this research process would not only enrich the lives of those who participated in it, but also my own. As I reflected in my own narrative:

Through this process, I have been allowed insight into, not only the lives of others who are chronically ill, but into my own. My somewhat isolated sense of being has shifted to that of shared camaraderie with those who so willingly shared their stories with me. The process has been cathartic in itself and I hope it has been so for those who participated in the research.

During the telling of the narratives, I noticed how the participants took numerous I-positions as they described their experiences. They reflected and engaged critically with their experiences and emotions as they considered how their illnesses had affected their lives on multiple levels. I had a sense that, for most of the participants, this was the first time that they had shared their experiences of illness in such an in-depth manner, with someone who had a deeper understanding of their struggles. Our dynamic interactions with each other, within the

context of this study, allowed us to engage in “critical self-reflection” (Hermans, 2013, p. 86). The research process enabled both the participants and I to reflect, dialogue and, subsequently, learn about ourselves.

This relates to the particular I-position that Hermans (2003, 2013) identifies as a meta-self, previously discussed in chapter two. One way of seeing this study is as a „dialogical space“ (Rule, 2004) in which we have created a dialogue with ourselves, each other and our illnesses, and with the wider scholarship on disability, learning and Dialogical Self Theory. Meta-positions allow for the separation of the self “from the ongoing stream of experiences and to place [ourselves] as authors, considering [ourselves] as actors in specific situations” (Hermans, 2003, pp. 122-123). This „distance“ and viewpoint allows us to consolidate and critically evaluate the I-positions we have adopted and the coalition of selves we have created.

6.5.1 The Meta-self and Reflections on Learning

Due to illness, the participants adopted specific strategies in terms of their learning. They adopted a meta-position in reflecting on their own learning, were able to develop strategies based on that reflection, and so „learn“ about themselves as learners, their own particular learning styles and factors that enable or constrain their learning. Through trial and error, the participants have developed these learning strategies. By taking a meta-position, standing back, and looking at these different aspects of themselves, they were able to consolidate and create a „new“ learning self that incorporates all the nuances of illness and learning. The participants reflected on how they had to find a balance that allowed them to move forward in their studies without irrevocably or severely jeopardising their health. Most of them have learnt how far they can push their bodies; how much work can be achieved in „one go“. They are cognisant of their strengths and weaknesses and factor that into their learning. By taking this meta-position, they are allowed to be more effective learners.

6.5.2 The Meta-self and Identity Formation

The research process, and in particular the narrative interviews, afforded the participants the opportunity to reflect upon their own identities. They developed their own sense of identity by adopting various stances in relation to their illness and to their studies. This was facilitated

by the ability to stand back (distancing) and look down from above (overarching perspective on various self positions), which led to „self-learning“. The following examples demonstrate this reflective meta-positioning:

Vanessa: When I look at myself and my future I know that I am going to have to do everything on my own. I know it's just going to be me.

Annah: In order for me to cope I have to a large extent had to change who I am. I can't push myself as hard as I always have.

These reflections show the participants considering who they were, who they are now and who they want or need to be in the future.

6.5.3 The Meta-self and Research

The process of research can create a „dialogic space“, a space for reflection and development of a meta-self. Throughout the research process I adopted various positions in the study such as, researcher and participant. Adopting a meta-position, enabled me to explore and develop a relationship between the two and come to a more holistic understanding of being and learning (and growing/thriving) as a chronically ill person. As I interacted with the participants and reflected upon their stories, I in turn reflected on my own. Finding parallels, I had to question certain aspects of how I understood myself as a chronically ill person and what that meant to me. Listening to Sasha's story and being astonished at how hard she was on herself, I had to question my deep empathy for her, yet my inability to afford myself the same empathy and compassion. As Josephine reflected on her illness as a „gift“, I was challenged to re-evaluate my understanding of my illness and its potential for positivity in my life. The „dialogic space“ of this research has become a space of both individual and collective reflection and relationship.

6.5.4 Developing My Meta-position from the Research Experience: Reflection

Being chronically ill forces us and allows us to live in ambiguity. We are many things. We do not fit neatly into a box stipulated by society. If we are open to it, in our ambiguity, we can learn to be free of restrictive black and white thinking, embracing the many shades of grey in-

between. We are able to consolidate our multiple disparate selves by taking up a meta-position that is able to accommodate contrasting and conflicting I-positions. Illness functions as a dialogical space that can facilitate learning about the self. Illness keys you into the body in such a way that it illuminates the complex inseparability of the mind, body and the self as a whole. We are dynamic, holistic organisms that influence and are influenced by our social interactions with others. I-am-ill, I-am-strong, I-am-weak and I-am-other and, that is „okay“.

6.6 Limitations

There are some limitations in this study. Due to the population's „hidden“ nature, it was challenging to find participants. This resulted in only a handful of participants. Although their narratives were extremely detailed and rich, they represented only a few voices from this „hidden“ population. All of the participants were women, which resulted in a dominant female voice and range of experiences. A male voice or presence in this study is missing. An additional limitation was the necessity to conduct one of the interviews via email. This created difficulties in facilitating a flowing narrative or uninterrupted storytelling. Although the participant answered all of my questions, due to the answer-question format that we fell into due to the email medium, stories that potentially could have been elicited by uninterrupted storytelling remained untold. Lastly, the experiences and challenges faced by the study's participants are not generalisable, but the findings may encourage further research in order to serve this population.

6.7 Future Research

The scope and nature of this dissertation could not possibly explore the entire range of experiences and challenges faced by adult learners with „hidden“ disabilities in the higher education context. Extended research that involves a larger number of participants from both genders, which includes all racial and cultural groups, would provide a more comprehensive understanding of this „hidden“ population. There is also a need for research on those who have not been officially diagnosed. Most chronic illnesses take many years before being officially diagnosed. Having no medical diagnosis makes accessing any official help at a higher education institution impossible, yet the person is no less disabled than their diagnosed counterparts. Research on younger chronically ill students, who have just entered higher education after high school, would provide an interesting comparison to mature adult learners

who are chronically ill. These are but a few research possibilities. Due to this population not being well researched in the higher education context, there are a multitude of research possibilities that are yet to be explored.

6.8 Conclusion

This chapter integrated and synthesised the discussions and findings that emerged from this study in relation to the research questions and relevant literature. The implications, insights and recommendations stemming from the research and an overview of the study's limitations, were discussed and a brief overview of possible future research was provided.

This study set out to understand the experiences and challenges faced by adult learners with „hidden“ disabilities in the higher education context. From this study, and the supporting literature, it is clear that the experiences and challenges of adult learners who are chronically ill are multi-layered and intertwined. The research in this dissertation reveals some of the ways that chronic illness impacts on the participants' lives and their learning. There is a dynamic interaction between identity, learning, illness, relationships, social roles and expectations. This study shows, that for these participants, the management of their learning is influenced and shaped by their ability to accept and incorporate illness into their identity, key into their own strengths and limitations and access social support systems available to them. Coping with chronic illness is physically and emotionally taxing, and this, combined with the stressors and strains of adult responsibilities and learning in higher education, creates a compounding system of factors that can seriously impede learning. Regardless of these major obstacles, these participants show remarkable strength and have pushed themselves beyond what is expected of the average student in order to achieve their goals. This study reveals a glimpse into the life-worlds of this under-researched „hidden“ population. It delves into the deeper stories of these women's lives, their struggles and their victories and is a burgeoning thread of a larger narrative to tell.

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APPENDICES

Appendix A: Individual Interview Schedule

Interview Schedule

The open-ended questions asked in these individual interviews will be semi-structured and based on the research questions indicated in the proposal. Other questions may flow from these main questions, depending on the information provided and how well the question prompts the person into sharing their experiences. Therefore, there needs to be flexibility in how the questions will be posed. The aim is to create a free flowing conversational interview that allows the participants to speak freely and provide them the opportunity to add to the interview issues they feel are important to them.

Interview Questions

1. Please explain the nature of your illness.
2. Tell me about the process of your diagnosis.
3. What was life like before you became ill?
4. How is your life now different?
5. Please tell me about the course that you are studying.
6. How does living with a chronic illness impact on your ability to learn and succeed in your education?
7. What coping techniques do you use to manage studying?
8. How would you describe yourself in terms of your illness?
9. How do you think your illness affects your identity?
10. How do you think others perceive you?
11. Who knows about your illness?
12. How and why did they get to know about it?
13. Under which circumstances do you tell people about your health condition?
14. What happens when you tell people about your health condition?

Appendix B: Coding Sheet

Coding Sheet

Disease/Illness

- Illness symptoms (DIS)
- Illness management (DIM)
- Illness beliefs, origins and knowledge (DIBOK)
- Illness acceptance/adaptation (DIA)
- Illness denial (DID)
- Illness overcompensation (DIOC)
- Illness impact non-specific (DII)

Support

- Family (SFA)
- Friends (SFR)
- Colleagues (SC)
- University (SU)
- Medical/Doctors (SM)
- Spiritual (SS)
- Supportive Disclosures (SD)

Non-support

- Family (NSFA)
- Friends (NSFR)
- Colleagues/Work (NSC)
- University (NSU)
- Medical/Doctors (NSM)
- Spiritual (NSS)
- Non-supportive Disclosures (NSD)

Learning

- Activities/Responsibilities (LAR)
- Management/strategies (LMS)
- Illness impact (LII)

Work

- Activities/Responsibilities (WAR)
- Management/strategies (WMS)
- Illness impact (WII)

Adult Responsibilities

- Activities (ARA)
- Management/strategies (ARMS)
- Illness impact (ARII)

Identity and Perceptions

- Identity roles (IR)
- Illness impact (III)
- Self (IPS)
- Others (IPO)
- Management of (IPM)

Emotions

- Anger (EA)
- Anxious (EAX)
- Aloneness (EAL)
- Betrayed (EB)
- Confusion (EC)
- Desperation (EDE)
- Disappointed (EDPD)
- Disbelief (ED)
- Doubt (EDO)
- Fear (EF)
- Frustration (EFR)
- Guilt/shame (EGS)
- Happiness (EHA)
- Hopeful (EHO)
- Helplessness (EHE)
- Overwhelmed (EO)
- Relief (ER)
- Sadness (ES)
- Self-doubt (ESD)
- Shock (ESH)

