

THE DIFFERENT VOICES OF CHRONIC ILLNESS

by

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I declare that **THE DIFFERENT VOICES OF CHRONIC ILLNESS** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

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ABSTRACT

This study aimed at exploring chronic illness from both the perspectives of the patient, living with the illness and the professional, treating the illness.

The epistemological framework is social constructionism. Qualitative research was selected as the research approach. Three in-depth interviews with three patients, suffering with a chronic illness were conducted, as well as three interviews with professionals, who had experience with patients diagnosed with chronic illnesses. Thematic analysis was the method used for the analysis of data.

The stories of the participants were reconstructed in terms of themes. A comparative analysis for both participants groups was done, and linked to the relevant literature

This study created an understanding of the complexity of chronic illness. The themes identified, highlighted the importance of the patient-professional relationship, specifically in the context of chronic illness.

Key terms:

Chronic illness; Healthcare; Medical model; Multiple 'voices'; Patient's perspective; Professional's perspective. Patient-professional relationship; Postmodernism; Purposeful sampling; Qualitative research, Social constructionism; Thematic analysis

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*Dedicated to, my mother-in-law,
Helena Viviers,
who is bearing her suffering from Lung Cancer
with courage and dignity.*

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CHAPTER 1

INTRODUCTION

When we believe we are seeing objects we are only seeing ourselves. We can really perceive nothing in this world except ourselves and the changes that takes place in us.

Georg Christoph Lichtenberg

Aphorisms

A Personal Statement

In Retrospect

After having completed this study, I, the researcher realised that the study became a representation of my own struggle when I commenced my studies in the field of Psychology. I was initially trained as a Dietitian and obtained a Bachelor of Science degree, my training firmly grounded in the medical model. After the completion of my studies, I practised Dietetics in various capacities, as a trainer of students, in a hospital context and in private practice. Over the years I became disillusioned with working from a paradigm that focuses on the disease process and not on the person as a whole. I felt at times ill equipped in my attempts to help my patients. This frustration led to my decision to pursue a career in Psychology, again seeking answers in how to help patients effectively. In Psychology, I entered the world of postmodernism and the construction of multiple realities, which allowed for new perspectives. However this paradigm, did not offer all the answers in dealing with the realities of those suffering from illness. Confronted with both worlds, I was still seeking answers, feeling the need to choose between the two. The answer was actually quite simple, as it lay within the stories of the participants of this study. For me, the patients' stories reflected the world of Psychology, a world with multiple realities and a world of compassion. On the other hand, the stories of the professionals represented the world of science and the medical model. On the surface, two different worlds, but as emerged from these stories, the worlds are connected through the humanness of the people representing them. Thus, a choice between the two is not necessary, it is not an either/or, but a both /and. For me this study emerged as a way of connecting these two worlds.

Introduction

Chronic illness is described as long-term and unpredictable in course, nature and outcome (Strause, Corbin, Fagerhaugh, Glaser, Maines & Wiener, 1984). The nature of chronic illness challenges both the patient, suffering from the illness, and the healthcare professional who is treating the illness. The patient needs to adjust his or her life to an illness that is incurable and unpredictable. The professional, who is trained to cure and 'fix' illnesses through the power of science, is confronted with illnesses that science can merely manage, not cure. Chronic illness today is still treated within a healthcare system dominated by the medical model, which primarily focuses on the illness and not on the person owning the illness. Treating chronic illness from this perspective seems to be limited and frustrating for both the patient and the professional. Therefore, the focus of this study is not the illness per se, but the experiences of both the patient and the professional within the context of chronic illness. This study thus adopted a social constructionist, as opposed to a medical, positivistic perspective, in order to achieve a fit with this focus.

Social constructionism focuses on the belief that "we socially construct reality by our use of shared and agreed meanings communicated via language; that our beliefs about the world are social inventions" (Berger & Luckman, cited in Speed, 1991, p. 400). Describing the illness experience from a social constructionist perspective does not imply that illness does not exist and that it is a mere social construction; it is grounded in the belief that the symptoms and the suffering from illness are real. However the meaning of the symptoms and the experience of the illness may be socially constructed (Eisenberg, 1988). This study will explore the experience of chronic illness from this perspective. In essence this study will aim to gain an understanding of chronic illness through exploring both the experiences of patients with chronic illness and the professionals who are treating chronic illness. The participants will be given the opportunity to tell their stories of their experiences and the meanings they attached to either living with or treating chronic illness. Exploring chronic illness from this perspective may therefore provide an alternative way of looking or add to the traditional ways of viewing chronic illness.

Explaining the Title

The title of this study, *The Different Voices of Chronic Illness*, will now be explained briefly. This title points to the essence of this study and as such sums it up. The study explores the experience of chronic illness from the different perspectives of the patient and the professional. These two perspectives may be regarded as different or even opposing, as the patient is the one suffering from the illness and the professional is the one treating it. Their worlds are connected by the occurrence of the illness, but it is viewed from different vantage points. The study aims to give the participants the opportunity to tell their stories within the context of chronic illness, thus giving them a 'voice'. Chronic illness is defined as a condition which lasts for a considerable period of time or has a sequelae which persists for a substantial period and or persists for more than three months in a year or necessitates a period of continuous hospitalisation for more than a month (Shiu, 2001). Chronic illness is regarded as long-term and unpredictable in course, nature and outcome (Straus et al., 1984).

Aim and Rationale of the Study

Traditionally acute and chronic illnesses are rooted within the world of medicine and healthcare which are dominated by scientific and technological discourses, embedded in the modernistic perspective. This traditional perspective does not seem to allow for the differentiation between acute and chronic illnesses. Acute illness seems to fit the medical model well, where the professional is the expert in eliminating the symptoms of the illness. However this traditional perspective of treating chronic illness as if it was an acute illness with an identifiable cause and of limited duration is limiting in the context of chronic illness which is long-term and unpredictable. The nature of chronic illness thus seems to require a broad range of knowledge and understanding to support the quality of life remaining for the individual with the illness (Casebeer & Verhoef, 1997) as opposed to simply treating and eliminating the illness of a patient when it is acute. Although much research has been conducted into chronic illness from a modernistic perspective, little research has been done on the experiences of those suffering from chronic illness or those

treating it. Therefore, the purpose of this study is to generate an understanding of the complexity of chronic illness, through the stories of patients' and professionals' experiences. Exploring chronic illness from a social constructionist perspective, which allows for multiple realities and prefers accounts based on a person's lived experiences may result in alternative ways in which to view and treat chronic illness.

The researcher aims to give a 'voice' to her participants, free of judgement or prejudice. She however acknowledges that her participation in the conversations and the final interpretation of the participants' stories may be coloured by her own perceptions, values and viewpoints. Therefore, the researcher acknowledges that the conversations with the participants and the final written product will be a co-construction between her own reality, that of the participants, as well as the literature consulted.

Creating a space where patients as well as professionals may share their unique experiences of either living with or treating chronic illness, will meet the aims of this study, which is to explore the different perspectives of the participants to create a deep and rich understanding of chronic illness.

The Design of the Study

Traditionally, research in healthcare or illness is strongly rooted in a modernist and positivistic paradigm (Casebeer & Verhoef, 1997). From the researcher's exploration of the literature it seems that although the positivist approach to research is still the dominant 'voice' within this field, a plea for alternative ways of exploring chronic illness is emerging (Casebeer & Verhoef, 1997; Sweeney & Kernick, 2002). By exploring the experience of chronic illness through the unique stories of patients and professionals it may add another 'voice' to the plea for new ways and avenues in the treatment of chronic illness within the current healthcare system.

Social constructionism is selected as the epistemological framework of this study. Social constructionism is concerned with "accounts that honor and respect the community of

voices inherent in each individual” and thus allows for personal accounts or stories that are based on unique and individual experiences (Doan, 1997, p. 131). Social constructionism, as an epistemology is founded within the philosophy of postmodernism, which will be discussed in Chapter 3.

A qualitative research approach as opposed to a quantitative research approach will be selected as it fits with the aims of the research which is to create an in-depth and rich understanding of the experience of chronic illness through the ‘voices’ of the participants. A qualitative research approach allows for an inquiry which “implies an emphasis on processes and meanings that are not rigorously measured in terms of quantity or amount” (Casebeer & Verhoef, 1997, p. 2). A qualitative research approach acknowledges the intimate relationship between the researcher and what is studied (Casebeer & Verhoef, 1997).

After the conversations with her participants, the researcher will reconstruct their stories in terms of themes. The themes identified from both participant groups, the patients and the professionals, will be discussed separately. In an attempt to include more ‘voices’ on the experience of chronic illness these themes will then be linked to the relevant literature. The researcher acknowledges that in her interpretations of these stories, she is looking through a lens coloured by her own realities at that specific point in time. Thus, the final presentation of highlighted themes and the comparative analysis of the themes may therefore represent a co-construction between the researcher’s reality, the participants’ reality and the literature. The design of the study does not necessarily allow for these findings to be generalised and to be extrapolated to a larger population, but may contribute significantly to our understanding of chronic illness.

Sampling and Selection

The researcher will make use of purposive and convenience selection. Participants will comprise two groups: Three individuals (patients) living with chronic illness and three health professionals working with chronic illness. Selection criteria for the patient group

will be based on diagnosis of a chronic illness, at least a year before the interviews for this study. A registered health care professional and extended experience with patients diagnosed with chronic illness will be the selection criteria for the professional group.

Collecting the Information

An in-depth interview will be used as the method to obtain information. The interview will take the form of a conversation. The questions asked will be open-ended, but focused on central themes around the experience of chronic illness. These themes may emerge from the conversations as well as from the researcher's own interests, and personal and professional experience.

Analysis of the Information

Thematic analysis, as an interpretive approach will be used to analyse the information. The researcher will follow the guidelines of analysis for the qualitative research interview as suggested by Kvale (1983).

In order to practically execute the study, the researcher will follow the following steps.

- The purpose and procedures of this study will be explained to each participant. Participants will be requested to give written consent to their participation, as well as to the tape recording of the interviews. An example of the consent form will be included under Appendix (i). The actual consent form of each participant will not be included in order to ensure their anonymity. Each participant will then be interviewed individually. The times and duration of the interviews will be scheduled according to the individual needs of the participants.
- The tape recorded interviews will then be transcribed. These transcribed interviews will be included under Appendix (ii) and Appendix (iii) respectively.
- Themes as identified through the researcher's lens will be allowed to emerge from each individual interview.

- Themes, from each participant group, namely patients and professionals will be discussed separately.
- This will be followed by a separate discussion of the themes of both groups and will be linked to the relevant literature.
- In the conclusion, an integration of the themes of both groups will be discussed.

The Format of the Study

This study will entail both a theoretical component and a practical component. The theoretical part will comprise a literature review, a discussion of the epistemological stance of this study, as well as a discussion of the research method to be used.

The literature review in this study will explore concepts such as chronic illness, the experiences of the patient and his or her family, as well as the experience of the healthcare professional. This provides both the researcher and the reader with a “background of the research” (Rapmund, 1996, p. 10). The literature review may also provide “an alternative voice with which the emerging themes can be compared” (Rapmund, 1996, p. 10). This will ensure a ‘multiple source of voices’ in creating an understanding of chronic illness from different perspectives. Incorporating all these different ‘voices’ in the exploration of chronic illness, is rooted in the belief of ‘multiple realities’, as informed by postmodernism and social constructionism.

In the practical part of this study the two groups consisting of three patients and three professionals will be given the opportunity to tell their stories within the context of chronic illness. Their ‘voices’ will be added to the voices of the literature. A third ‘voice’ that of the researcher, will also be added as she will engage in the conversations and interpretations of the participants’ stories, guided by her own realities. Thus, the exploration of chronic illness in this study will be a co-construction of the participants’ stories, the literature and the researcher’s own story. However, the participants’ stories will be highlighted as the dominant ‘voices’ of this study.

Presentation of the Study

This study will comprise the following chapters.

Chapter 2 will firstly comprise a discussion of chronic illness as defined within the current health care system. The difference between acute illness and chronic illness, as well as the nature of chronic illness will be highlighted. Models of illness will be discussed in terms of their effectiveness in the treatment of chronic illness. This will be followed by a discussion on the experience of the patient who is suffering from a chronic illness. In exploring the experiences of chronically ill patients, various authors described coping and adjusting strategies for the chronically ill. This chapter will reflect on some of these findings. The experience of the families and loved ones of chronically ill patients will be explored in terms of the social dilemma brought on by the illness experience. Finally, the role of the professional, specifically within the context of chronic illness, will be discussed.

Chapter 3 will entail a discussion on social constructionism as the selected epistemological stance of this study. Firstly, postmodernism, as the broader philosophy, in which social constructionism is rooted, will be discussed. This chapter will briefly refer to modernism to highlight its differences to the epistemology of postmodernism. Thereafter, the basic assumptions of social constructionism will be explored, as well as its practical implications within the context of this study. In addition, this chapter will refer to other researchers who attempted to describe illness, not only as a biological phenomenon, but also as a social construct.

Chapter 4 will describe the research method that this study will follow. The characteristics of the qualitative research approach and its consistency with the epistemology of social constructionism will be explained. Methods for obtaining information and the analysis of this information will be discussed. Thematic analysis as an interpretive method of data analysis, along with its practical implications for this study, will be explained.

Chapter 5 and **Chapter 6** will be the reconstruction of the stories in terms of the themes that emerged from the patients' and the professionals' stories. The transcribed interviews from which the themes emerged are attached as Appendix (ii) and Appendix (iii).

Chapter 7 will be the comparative analysis, firstly between the themes of the patients and the relevant literature, followed by the themes of the professionals in relation to the relevant literature.

Chapter 8 will be the concluding chapter for this study. A brief overview and evaluation of the study, in terms of its strengths and limitations, will be discussed. An integration of the themes of both participant groups, highlighting the importance of the patient-professional relationship in the context of chronic illness is provided. Further recommendations in clinical practice and future research will be discussed.

Conclusion

Very little attention has been paid to the experiences of patients with chronic illness and the professionals treating chronic illness. The focus of existing research is the illness per se and not necessarily the individual's unique experience within the context of chronic illness. This study therefore attempts to address this shortcoming by giving a 'voice' to patients as well as professionals, and to the relationship that exists between them by employing a qualitative method within a social constructionist framework.

CHAPTER 2

CHRONIC ILLNESS: THE PATIENT, THE FAMILY AND THE PROFESSIONAL

There are three factors in the practice of medicine; the disease, the patient and the physician. The physician is the servant of the science, and the patient must do what he can to fight the disease with the assistance of the physician.

Hippocrates Epidemics, 1, 2.

Introduction

This chapter explores different definitions and explanations of key concepts of the study. It begins with a historical overview of illness. Then some definitions and models in explaining chronic illness will be explored. This will be followed by a discussion on the experience of the person with chronic illness, the experience of the family living with chronic illness and the perspective of the health professional treating the individual with chronic illness.

Brief Historical Overview of Illness from Ancient to Present Times

Throughout the history of man, health and illness have formed an integral part of human experience. Dimond and Jones (cited in Pallourious, 1992) describe how throughout the recorded history of all cultures and societies, the sick and the disabled have been a focus of special attention.

In ancient Hebrew culture, illness was regarded as punishment from God for sins committed. The ancient Greeks treated their ill as being socially inferior. Conversely, Christianity viewed the suffering of the ill as an indication of God's special favour.

The Age of Science followed which gave rise to the notion that illness was caused by natural conditions beyond the control of the afflicted person. The way in which society today views people with illness is a combination of the Hebrew, Greek, Christian and scientific perspectives. (Dimond & Jones, cited in Pallourious, 1992).

Herzlich and Pierret (cited in Struckman, 1994) noted that since the 1980's there seems to be a shift towards health being a person's responsibility. Health has become a supervalue, an end in itself and therefore, in our society people will try to do everything possible to avoid becoming ill (Herzlich & Pierret, cited in Struckman, 1994).

It is within this context of health as a supervalue and a personal responsibility that people afflicted with illness today have to find a sense of self-worth and meaning in living with illness.

Differentiating between Acute and Chronic Illness

Modern medicine differentiates between acute illnesses and chronic illnesses.

An acute illness is typified by a short period of intense illness from which the patient usually recovers very quickly (Shiu, 2001). Acute illnesses are mostly caused by bacteria and parasites. Due to the discoveries of modern medicine, these illnesses can be cured effectively (Straus, Corbin, Fagerhaugh, Glaser, Maines & Wiener, 1984).

A chronic illness is defined as a condition which lasts for a considerable period of time or has a sequelae which persists for a substantial period and /or persists for more than three months in a year or necessitates a period of continuous hospitalisation for more than a month (Shiu, 2001).

In 1965, the Commission of Chronic Illness of the United States of America defined chronic illness as, “all impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation, or care” (Straus et al., 1984, p. 6).

Lubkin, in differentiating between acute and chronic illness, uses the metaphor of a visitor to a household. An acute illness may be compared with an unexpected visitor who leaves one’s house after a short-term stay (cited in Pallourios, 1992).

Chronic illness on the other hand announces plans to visit for an indefinite stay and gradually becomes part of the household. Although this guest is a welcome alternative to death, the illness provides a mixed blessing to the host household and to society at large (Lubkin, cited in Pallourios, 1992, p. 2).

The emphasis of this study will be on chronic illness which will be described in some detail.

The Nature of Chronic Illness

Straus et al. (1984) define the nature of chronic illness according to a number of socio-medical and psychological characteristics:

- i) *Chronic illnesses are long-term by nature.* The time scales for the treatment of acute illnesses usually span days or weeks. A cure or a significant improvement in the patient’s condition may be achieved soon after starting treatment. Chronic illnesses have a long-term nature that requires ongoing interaction between patients and health professionals over months and years.

- ii) *Chronic illnesses are unpredictable or uncertain in course, nature and outcome.* Prognosis is often uncertain in chronic illness. The evolving, unpredictable course of the illness provides the information to make possible assumptions on what is going to happen and when. These uncertainties may bring considerable stress to the patient as well as to the health professional. The nature of the uncertainty of the illness may subject the patient to various new treatments and technologies in an attempt to bring the illness under control.

- iii) *Chronic illnesses require proportionately greater efforts at palliation.* The nature of chronic illness may subject the patient to discomfort, pain, restricted activity and quality of functioning. The efforts of the health professional may be to relieve these 'symptoms' without providing any form of 'cure'. The treatment prescribed may also be the cause of restricted quality of life and the source of symptoms. These efforts by the health professional to control the illness and relieve the symptoms may become a balancing act between what the professional regards as 'medically necessary' and the quality of life of the patient.

- iv) *Chronic illnesses are multiple illnesses.* Chronic illnesses are systemic and degenerative in nature; chronic illnesses tend to multiply themselves. The long-term breakdown of one organ or physiological system may result in the greater involvement of other organs or systems. The long-term disability caused by a chronic illness may make the afflicted person more vulnerable and susceptible to other additional illnesses. The treatment, possible chemotherapeutic agents and surgical procedures may often cause iatrogenic disabilities. This refers to disabilities caused by the treatment itself; for example, certain types of chemotherapy in the treatment of cancer may result in vulnerability for infections as it attacks the immune system as well as the cancer. The psychological stress that the patient may experience as a result of constantly adjusting to the course and treatment of the illness may become a factor contributing to additional medical complications. Patients may become depressed as a result of feeling

there is no hope. Loss of hope and Depression may lead to non-compliance of treatment that may lead to further medical complications. Depression and chronic stress may also have an effect on the immune system and make patients more vulnerable to other illnesses.

- v) *Chronic illnesses are disproportionately intrusive.* This means that the illness may intrude in many areas of the patient's life. The patient needs to adjust to the demands of the treatment as well as to the inactivity the illness might impose. The illness is life-long and the patient is expected to continue with normal daily activities; this may require a reconstruction of the manner in which the patient conducts his or her life. The reconstruction may affect the patient's household routines, occupation as well as intimate and social relationships.

- vi) *Chronic illnesses require a wide variety of health professionals and services.* Depending on the severity and the complexity of the illness, the person may require the services of a large number of health professionals; for example, doctors, nurses, social workers, psychologists and occupational therapists may all be involved during the course of a chronic illness.

- vii) *Chronic illnesses are expensive.* By nature, chronic illness demands routine monitoring, frequent visits to health care professionals, and use of long-term expensive medications, regular hospitalisations and expensive surgical or medical procedures.

It may be concluded that the nature of chronic illness is long lasting, often life-long. The symptoms may not be present all the time, but they are recurring which make the prospects of a cure limited. Therapeutic intervention and treatment are directed at symptomatic relief and some form of control over the illness. The treatment in itself may be a source of symptoms and restriction of activity.

The drawn-out nature of the illness requires the person to integrate the illness into his or her daily life. The illness becomes part of the person's existence. The meaning a person attributes to the illness in his or her life largely depends on factors intrinsic to the illness such as the nature and severity of the illness, as well as on factors intrinsic to the social status of the person such as age, gender, occupation, achievements and obligations (Dalal, 2000). The afflicted person is expected to make the adjustments needed to live with the illness in the world of the healthy.

Models of Illness

Various models of illness are described in the literature. These models do not differentiate between acute and chronic illness. When one considers the difference between acute and chronic illness as well as the nature of chronic illness, it is evident that applying the same model to both chronic and acute illness may be problematic for the patient as well as the professional treating chronic illness. Different models of illness will be described and evaluated in terms of their effectiveness as models of chronic illness.

The Medical Model

Traditionally the illness experience has mainly been conceptualised from the medical model. Illness is conceptualised as the individual's experience of symptoms (Morse & Johnson, 1991). The medical model is still the dominant model in the description of the experience of illness today. Alonzo (1984, p. 499) describes the medical model as follows:

The medical model generally focuses on biological or physiological disturbances resulting from infectious or parasitic agents, genetic error or variations, nutritional or dietary deficiencies, trauma or long-term stress and psychological and psychosomatic factors.

The medical model refers to the diagnosis and treatment of illness through the use of published standardised categories agreed on by the medical community (Hall, 1996). The medical model assumes that for each diagnostic category there is a current or there will be a future medical cure. This model also assumes that illness originates from inborn or acquired biological characteristics interacting with factors such as lifestyle, personal and family dynamics, and life experiences (Hall, 1996).

The training of health professionals within this model has focused on illness and treatment processes (Morse & Johnson, 1991). It is believed that certain mainly physical factors cause illness and if these factors can be identified and treated, there will be a predictable outcome - the illness will clear up. Health professionals are trained to be 'holders' of expert knowledge gained through scientific research. The health professional is viewed as the expert. The professional decides what the patient needs to know to manage his or her condition (McIver, 1999). This expert knowledge is based on the biological and medical view of illness rather than on knowledge from the patient's unique experience. Professionals focus on pathological processes; their interest revolves around the individual's experience of physical symptoms as cues to underlying disease processes. There is an emphasis on the physiological aspects of disease rather than on the emotional and psychological responses to illness (Morse & Johnson, 1991). Alonzo (1984) states that although certain subspecialties within medicine acknowledge psychological etiology and psychological disease, and health professionals in their training are ideally sensitised to psycho-social difficulties, the primary emphasis within the medical model remains physicalistic. This model reduces the patient to his or her physical parts; the person is treated as a disease rather than a person with a disease (Morse & Johnson, 1991).

The medical model has provided revolutionary advances in the cure of various illnesses. The use of antibiotics and vaccines provided prevention and cure for many life-threatening diseases and disabilities. The advances made by medical technology included organ transplants, test tube babies and dialysis. The medical model as practiced in medicine today, is thus best suited for the treatment of acute illnesses and may have

limitations in the treatment of the chronically ill (Dalal, 2000). This may be due to the fact that medical treatment and procedures treat patients as passive recipients of the treatment whereas the nature of chronic illness calls for the active involvement of the afflicted person (Dalal, 2000). Dalal (2000) states that any model of treatment for chronic illness has to take into consideration the person's own understanding of the illness as well his or her way of dealing with the illness in his or her living context. In spite of the accomplishments of the medical model, the permanency, the uncertainty, the incurability and the degenerative nature of chronic illness are challenging the effectiveness of this model in patients suffering from this kind of illness. Chronic illness seems to lack a fit with the medical model.

Alternative Models and Perspectives of the Illness Experience

Although the medical model is the most dominant in the practice of medicine today, other models of illness emerged, as an alternative or supplementary to the medical model. These models, like the medical model, do not distinguish between acute and chronic illness. The effectiveness of these models in chronic illness will be discussed.

The Health Belief Model

The Health Belief Model (HBM) was developed in the early 1950s by a group of social psychologists to predict preventative health behaviours such as participation in immunisation and screening programmes (Janz & Becker, 1984). The model was further developed to predict behaviour during illness through an understanding of an individual's beliefs of personal control in the illness experience (Pallourious, 1992). The nature of chronic illness mainly demands compliance to specific prescribed health behaviours or regimens from its sufferers; this makes the HBM relevant in the search for a better understanding of the illness experience.

According to Janz and Becker (1984), the HBM consists of the following dimensions:

perceived susceptibility, perceived severity, perceived benefits and perceived barriers, which will now be explained.

Perceived susceptibility. This dimension refers to an individual's subjective perception of the risk of contracting a condition. Individuals vary in their feelings of personal vulnerability to an illness or condition.

Perceived severity. This dimension refers to an individual's perception of clinical or possible social consequences of the illness. How individuals evaluate the consequences of an illness such as possible pain, disability, the effects of death on family life and occupation will vary widely from person to person.

Perceived benefits. How an individual perceives the benefits and the effectiveness of prescribed health behaviours to reduce the illness threat will affect the individual's compliance. The individual will evaluate the recommended health action in terms of efficiency and feasibility.

Perceived barriers. The perceptions of the negative aspects of a particular health action may determine compliance. Perceptions may include expense, inconvenience, time-consuming nature or unpleasantness, such as pain and side effects.

The dimensions of the HBM have proved to be important in the understanding of an individual's attitudes towards a particular illness and therefore, are used as a predictor of behaviour in the illness experience (Pallourious, 1992). Janz and Becker (1984) conducted a critical review of HBM-related studies published during the period 1974-1984. They concluded that the HBM might be used as a significant predictor of health related behaviours in illness. They also concluded that the Health Belief Model is a psychosocial model which focuses on beliefs and attitudes. It however, excludes other factors outside the scope of the model which may also predict possible health related behaviors.

The HBM, like the medical model does not differentiate between acute and chronic illness, but focuses on illness in general. The model does allow for a shift from regarding illness as only a biological phenomenon and recognises the experience of the person with

the illness as a factor in the course of illness. This acknowledgement of the person's perceived experience may make the HMB a valuable tool in understanding and treating chronic illness. If the HBM can be used in conjunction with the medical model it may help professionals to have a better understanding of the patient's experience.

The Sociological Perspectives

The sociological perspectives refer to the structural functional perspective and the interactional perspective which are the two primary approaches to health and illness within sociology (Alonzo, 1984). The structural functional perspective is also referred to as the positive orientation and the interactional perspective as the ideational orientation (Twaddle & Hessler, cited in Alonzo, 1984).

The structural functional perspective. The structural functional perspective is described by Cockerham (cited in Alonzo, 1984) as being similar to the biological concept of homeostasis. Society, rather than the body, attempts to maintain an equilibrium of a harmonious pattern of shared norms and values. Society, as the body, establishes the regulatory processes to maintain equilibrium. Illness is seen as dysfunctional because it threatens the equilibrium by interfering with normative and social values. The function of the health professional is to offset the dysfunctional aspects of illness by curing and preventing illness (Alonzo, 1984). According to Alonzo (1984), the strength of this model is the focus on etiological illness processes which refer to structural variables that are socially defined such as age, sex and socio-economic status.

The interactional perspective. The interactional perspective focuses on the processes of illness definition and evaluation and their social consequences. This model accepts the biologic symptoms of the illness, but argues that how the person and society defines the illness may have significant consequences for the diagnosis and prognosis of the illness process (Alonzo, 1984). How the person experiences the physical symptoms of illness and the explanation he or she and society attach to it may have an effect on the outcome of the illness. Illness is viewed as a social situation, which refers to a "combination of

physical reality and social evaluation and response” (Lober, cited in Alonzo, 1984, p. 500). Thus, within this model the focus is on the understanding of the symptoms and signs of the illness within the social context within which it occurs. The model refers to the interaction in illness between the person’s body, his or her physical environment as well as the social environment. The model does not differentiate between acute and chronic illness. The focus of this model is the meaning that individuals will attach to the reality of the symptoms of the illness that they experience. The meaning will be influenced by the individual’s physical, situational and social context. This model also acknowledges the experience of the individual and therefore, can be used in the understanding of chronic illness.

The Illness Constellation Model

Morse and Johnson (1991) developed the Illness Constellation Model with the emphasis on illness as an experience that affects the sufferer as well as his or her significant others. The focus of this model is the impact of illness on the interaction between the sufferer of the illness and his or her significant others. The fact that the illness experience involves not only the sufferer, but also those who are close to him- or herself are emphasised by the Illness Constellation Model.

The Illness Constellation Model is defined as a four-stage process (Morse & Johnson, 1991):

Stage I: Stage of uncertainty. This is the stage where the individual detects or suspects signs of illness and attempts to make sense of these symptoms by determining their severity and meaning. This is also the stage where the significant others may observe that the affected person is ill. Alternatively, the affected person may have to share the possibility of illness with his or her significant others.

Stage II: Stage of disruption. This stage begins when the individual acknowledges that the illness is real and decides to seek help. This stage may also be initiated by the confirmation of a medical diagnosis. Alternatively the affected person may become so ill

that the decision to seek help is made by others. This is a stage of crisis. The person may relinquish control and withdraw from the situation (illness) by distancing him- or herself. The control may be given to health care professionals or to family members. This is also a stage of crisis for the significant others. They become aware of the possible threat of illness to their loved one.

Stage III: Stage of Striving to Regain Self. This is the stage where the affected person strives to make sense of the illness. The person explores possible causes and tries to predict future consequences. His or her significant others respond by committing to the fight against the illness by supporting the affected person. The affected person focuses on preserving him- or herself; this involves conserving energy. The significant others try to buffer the ill person against any undue stressors. In this process the ill person may become passive. He or she needs to negotiate for self-identity and self worth. He or she is in constant negotiation to prove that previous roles can be resumed. The significant others are involved with a balancing act to allow the ill person to resume previous roles, but also preserve energy to fight the illness.

Stage IV: Stage of Regaining Wellness. In this stage the ill person attains mastery by regaining former relationships and control of self. The person determines if he or she is better and adjusts to and accepts if there is a change in the level of functioning. The ill person focuses on taking control, learning to trust his or her body, monitoring signs and symptoms, and accepting the limits set by the illness. The significant others support the process in which the ill person is regaining control of his or her life.

According to the authors, the Illness Constellation Model is not an attempt to develop a standard response to the illness experience, but tries to provide a better understanding of how the affected person and significant others respond to the experience of illness (Morse & Johnson, 1991). The model is also not an attempt to describe a linear process, but a reciprocal process of regression and progression between the stages (Morse & Johnson, 1991). This may be a very effective model in chronic illness as chronic illness affects the afflicted person's relationships with significant others and forces the person to redefine roles and relationships.

The alternative models discussed all provide a different understanding of illness to the medical model and are thus useful especially in the treatment of chronic illness.

In conclusion, the importance and stature of the medical model in treating illness cannot be denied. Nonetheless, the nature of chronic illness may therefore require an integration of the medical model with alternative models that acknowledge the patient's experience, his or her social context as well as relationships with significant others.

In this section of the literature the key concepts of the study were explored. The nature of chronic illness and the main paradigm within which it is conceptualised were defined. The paradigm shifts or alternatives on how illness is perceived were also discussed. The next section will review the literature on the illness experience from the patient's perspective.

Adjusting to Illness: The Experience of the Patient

The discussion will focus on the patient's process of adjustment to chronic illness. Chronic illness challenges its sufferers to adjust to its unpredictability as well as its degenerative nature. The person has to go through a process of achieving meaning and quality of life in spite of the chronic threat of illness. Themes identified in the process of adjusting are self-esteem, a feeling of loss of identity, a search for meaning and the possibility of achieving a sense of mastery and the restoration of self-esteem.

The nature of chronic illness demands its sufferers to adjust continuously to the degenerative nature of the illness and its consequences. Researchers are therefore interested in how people adjust to threatening events such as a serious chronic illness. Silver and Wortman, (cited in Taylor, 1983) state that despite serious setbacks such as a personal illness, the majority of people facing such threatening events achieve a quality of life or level of happiness equivalent or even exceeding their prior level of satisfaction. As a result of her work with cancer patients, cardiac patients and rape victims, Taylor (1983) proposed a theory of cognitive adaptation to threatening events.

Taylor (1983) defined an adjustment process that centers around three themes; namely a search for meaning in the experience, an attempt to regain mastery over the event in particular and over one's life, and an effort to restore self-esteem through self-enhancing evaluations.

The Search for Meaning

The search for meaning involves the need to understand why a crisis has occurred and what its impact has been. People confronted with a threatening event like a personal illness will make attributions in an effort to understand, predict and control their environment. People will try to establish the cause of the event; by understanding the cause they may find the significance of the event in their lives and realise what it symbolises in their life. In chronic illness, the majority of patients will attribute their illness to some kind of event or theory. Taylor (1983) reported that the majority of cancer patients in her study attributed their cancer to general stress or to a particular stress.

The search for meaning also involves the exploration of the implications of the illness and its consequences for one's life. In her interviews with patients, Taylor (1983) reported that in some cases the illness experience resulted in a new positive attitude to life. However, not every one of the participants in Taylor's study could construct positive meaning from the illness experience. Those who were able to construct a positive meaning showed significantly better psychological adjustment.

Gaining a Sense of Mastery

A sudden threatening event like a serious illness can easily undermine one's sense of control over one's body as well as one's life. The adjustment process involves gaining a feeling of control over the illness. A sense of mastery may be achieved by beliefs of personal control over the illness or direct behavioural efforts to control the illness. The

person may control the illness by gaining knowledge of it, or changing his or her diet or by following health professionals' advice thoroughly.

The Process of Self-Enhancement

The third theme in the process of adjustment involves the efforts to enhance the self and restore self-esteem. Self-esteem has been defined by Coopersmith (1968) as the self-appraisal of one's significance, worth, competence, and success as compared to others (Malcarne, Hansdottir, Greenbergs, Clements & Weisman, 1999).

Being confronted with a threatening event such as illness may lead to a drop in self-esteem and self-regard. In illness, after such a drop in self-regard is experienced, people tend to use cognitive efforts to pull themselves out of their low self-regard. In her study, Taylor (1983) reports some of the esteem-enhancing cognitions participants used to restore self-esteem and self-regard.

Social comparison contributed to the self-enhancing efforts of patients in Taylor's study. Comparing one's self to someone that you believe is worse off is a self-enhancing cognition to bolster self-esteem. In Taylor's study of breast cancer, the women who were treated with selective surgery thought they were much better off than those who had a mastectomy; the older woman who had a mastectomy considered themselves luckier than younger woman in a similar situation. Dewar and Lee (2000) reported a similar strategy in patients with severe spinal injuries of boosting self-esteem by comparing themselves to those who were regarded worse off than you. For example, patients who were diagnosed as quadriplegic directly after injury considered themselves better off than paraplegics that deteriorate over time into being quadriplegic.

Taylor (1983) concluded that successful self-enhancement in the process of adjustment depends on the ability of the individual to sustain and modify cognitions or illusions that buffer against the present threat of illness as well as against possible future setbacks. The literature also reports that not all chronically ill sufferers are able to resolve the issue of

negative self-esteem. According to Symister and Friend (2003), self-esteem is not only mediated by the cognitive adjustment to illness, but also by factors such as social support, optimism and mood.

Dewar and Lee (2000) support the theory of cognitive adaptation proposed by Taylor (1983). In their study with sufferers of catastrophic illness and injury they found a similar process of adjustment to the threatening event. They proposed an adjustment process involving three stages: finding out, facing reality and managing reality. The finding out phase entails the initial feelings of being overwhelmed by the diagnoses, the relief of knowing what is wrong and the anxiety of sharing it with others. In this stage affected individuals also make use of cognitions or illusions to make their situation more bearable. In the second phase, facing reality is where the individual develops an understanding that he or she has limited choices and that the present circumstances might not change and might even deteriorate. In the final phase managing reality is where the individual makes an effort to continue with life in spite of his or her different circumstances. Managing reality does not imply that problems and emotional responses are totally removed, but that strategies and cognitions are developed to limit or bear the amount of suffering.

The following theme is also identified as important to the patient's process of adjusting to chronic illness.

The Loss of Identity

Chronic illness may cause setbacks, flare ups, complications, impaired functions as well as social, psychological and financial consequences. All these factors may impose identity problems for those affected by illness (Charmaz, 1987). The disrupting effects of illness in one's life may force a process of managing and restructuring identity. An illness confronts a person with how much of one's identity is tied up with the loss of ability that an illness may bring (Fitzpatrick, 2002). The challenge to the identity emerges from the threat to the physical self which may be experienced as a loss of the core sense of the self (Fitzpatrick, 2002). A change to one's health status forces an evaluation of the self as well as a sense of self in relation to others (Fitzpatrick, 2002).

It seems that these identity challenges, the chronic ill person experiences, are part of the process of adjusting to chronic illness.

Concept of identity

The concept of identity refers to attributes, actions and appraisals of self. Social identity derives from such identifications others make, personal from identifications the individual makes (Charmaz, 1987, p. 284).

Charmaz (1987) viewed identities as influencing and shaping the evolving self. The individual may base the personal identity on socially defined images of the self. Identity may be seen as a continuous process, as it may shift or change as a person reflects on the images and identifications that the self and others confer upon him. The event of a chronic illness may shift these identities.

Charmaz (1987) in her study analysed the experiences of chronically ill people whose former identities were challenged. Accounts of the experiences of the participants revealed two interconnected issues involving with the search and development of new identities in the chronically ill: the role of preferred identities and the development of identity hierarchies.

Preferred identity The concept of identity also accounts for an individual's aspirations and motivation for future identities (Charmaz, 1987). It is this future or preferred identity that encompasses the individual's hopes, objectives, aspirations and goals, which are challenged by chronic illness (Charmaz, 1987).

Identity hierarchy Charmaz (1987) found that ill people experience a hierarchy of preferred identities. The preferred identities change according to this hierarchy as the

illness progresses. The types of preferred identities constitute particular identity levels in the hierarchy. Charmaz (1987) identified four identity levels: the supernormal identity, the restored self, the contingent personal identity and the salvaged self. The experience of progressive illness may force a person to reduce identity goals and aim for a lower level of preferred identity.

The supernormal identity: This is the most difficult level of identity to maintain or achieve for a sufferer of a disabling illness. The supernormal identity represents levels of success and social acclamation in the competitive world. The person with the illness over-achieve in comparison to 'normal' people despite the limitations of his or her illness.

The restored self: The restored self represents the level which assumes a return to the former self despite the consequences of the illness. People on this level of identity do not only aim for a reconstruction of the physical self as before the illness, but also assume continuity with the self as before.

A contingent personal identity: This level of identity represents possibilities for the self as well as the realisation of possible failure. People who adapt a contingent identity usually first aimed for a supernormal identity or restored self, but failed to realise either one of them.

A salvaged self: This level of identity represents the position where the person with the illness attempts to define the self as positive and worthwhile despite the consequences of the illness. People at this level present themselves as positively as possible despite the adverse circumstances of their present existence. They have realised the impossibility of attaining an independent, self-sufficient identity in the outside world. The salvaged self will aim to continue some favourable attribute or activity from the past.

Charmaz (1987) concludes that people with illness aim for the different identities during specific phases in their illness. Charmaz (1987) also reported that in her study some

participants were so overwhelmed with the loss that they had great difficulty realising any positive self-image or identity. However, most of the participants in her study were able to create, adapt and reinvent their lives to maintain a positive identity.

The burden of chronic illness and the process of adjustment are complex. Problems in chronic illness are ongoing and the suffering continuous. Adjustment requires the chronically ill to be involved in an ongoing process of rebuilding an image of themselves, manage their daily lives as well as preserve their relationships with others (Dewar & Lee, 2000).

Mood and Depression in Chronic Illness

Depression, diagnosed as Major Depressive Episode, clinically presents with a marked depressed mood as well as diminished interests or pleasure in activities, thoughts and feelings of worthlessness as well as thoughts of death. Other symptoms may include changes in weight, sleep disturbances and psychomotor agitation and retardation (Kaplan & Sadock, 1994).

Various studies have explored the relationship between Depression and chronic illness. Depression as an etiological factor in the onset of illness has been explored as well as the effect of illness on mood and emotional disorders (Johnston, 1999). The consequences of Depression or emotional states on the progression of illness are also a focus of study. Other studies have explored treatment or remedies for people with physical illness who are in distress (Johnston, 1999). Johnston (1999) in a critical review of studies exploring the relationship between mood and illness concluded that mood or Depression as an etiological factor in illness onset is well documented. On the other hand, it seems that the effect of mood on illness progression is vague and the results of studies inconclusive.

Mood as an Etiological Factor on Illness

Steptoe (cited in Johnston, 1999) argues that studies exploring mood as an etiological factor in illness have achieved a considerable degree of coherence. This may be due to progress in the field as a result of the combination of longitudinal, predictive studies and studies of people living with chronic stress combined with experimental studies of animals subjected to chronic stressors. The various developments in endocrinology and immunology with resulting advances in psychoneuroimmunology have led to a better understanding of mood related factors on disease onset.

Researchers have attempted to establish an etiological link between Depression and the onset of Diabetes. The aim of this research was to identify the 'so-called' diabetic personality. A cluster of personality attributes underlying Depression which predisposes the person to Diabetes was identified (Gregg, Robertus & Stone, 1989). However, Lustman (cited in Gregg et al., 1989) concluded that these studies had methodological problems and that it is not known whether Depression is caused by or contributes to metabolic instability in the onset of Diabetes.

The research on the existence of a diabetic personality was therefore not conclusive, but the impact of the experience of Depression and anxiety on disease outcome led to further research (Gregg et al., 1989). Grant, Kyle, Teichman and Mendels (cited in Gregg et al., 1989) assessed what impact life events had on the onset and outcome of Diabetes. Results suggested a relationship between the occurrence of life changes for patients and aggravated diabetic states. This relationship was especially significant for undesirable events possibly associated with a depressed mood (major financial difficulties, marital separation, law violation, job demotion or termination, death of a close family member, major personal illness or injury).

A study conducted by Grant et al. (1974) supported an earlier study of Slawson, Flynn and Kollar (1963) where 14 of the 25 newly diagnosed diabetics in their study reported a

major significant negative event which was associated with loss prior to diagnosis (Gregg et al., 1989).

These studies implicated psychological stress which resulted in mood disturbance to have an etiological role in the onset of Diabetes, possibly by triggering the initial metabolic imbalance leading to Diabetes in genetically predisposed individuals (Gregg et al., 1989).

The impact of mood and emotional stress on illness onset in Arthritis has been well-documented (Gregg et al., 1989). Studies have revealed that a significant number of individuals diagnosed with Rheumatoid Arthritis have reported experiencing emotional traumatic events, possibly associated with depressed mood within six months prior to the onset of the illness (Gregg et al., 1989). Baker (1982) suggested evidence of the role of emotional stressful events in early life influencing the development of Rheumatoid Arthritis in later life (Gregg et al., 1989).

Similar findings concerning the onset of Multiple Sclerosis are documented. Psychological stresses such as psychological pressure and feelings of helplessness have been found to contribute to the onset and exacerbation of the symptoms of Multiple Sclerosis (Gregg et.al. 1989).

It may be concluded that mood symptoms, such as those experienced in Depression seem to play a role in the onset of many of the major known chronic illnesses such as Diabetes, Rheumatoid arthritis and Multiple sclerosis.

Effect of Illness on Mood and Depression

Are individuals suffering from chronic illness more depressed than others? This question has been researched extensively, resulting in conflicting conclusions. These conflicting results are a result of differences in research protocols for assessing Depression as well as individuals' different responses to illness (Johnston, 1999). In a critical review of studies exploring the relationship between Depression and illness, Johnston (1999) concludes:

Taken together, these theoretical approaches and related findings suggest that people with chronic disease will be more distressed if the disease is more severe, they perceive it to be severe and to have many symptoms, they attribute it to themselves, it is seen as chronic, they anticipate little control or cure, they experience or expect undesirable consequences, they use avoidant coping, and they have little social support (Johnston, 1999 p. 79).

The following were studies conducted to determine the relationship between Depression and chronic illness as a result of individual differences and perceptions as well as differences in illnesses, have contradictory findings.

In their study on the relationship between Depression and chronic illness in adolescents Key, Brown, Marsh, Spratt and Recknor (2001) found that adolescents with chronic illness had a higher incidence of self-reported symptoms of Depression than healthy controls. The specific illness had an effect on the frequency of depressive symptoms: adolescents with Sickle cell disease reported the highest frequency of depressive symptoms compared to adolescents suffering from various other illnesses such as Asthma, Diabetes, Cystic fibrosis, Spinal bifida and Cerebral palsy. Adolescents who rated or perceived their illness as moderate or severe reported more depressive symptoms than those who rated their illness as mild. However, the incidence of self-reported severity of depressive symptoms did not correlate with the health care providers' ratings of the severity of the illnesses.

In a study to determine the relationship between Depression and quality of life in individuals with Multiple Sclerosis, Depression and quality of life were determined by the patients' perception of support, self-esteem and locus of control over health. Depressed individuals tended to over-report poor social adjustment and negative life events as well as dissatisfaction with social roles (Wang, Reimer, Metz & Patten, 2000).

Chou and Chi (2002) investigated the extent to which chronic illness contributes to depressive symptoms in the older members of a Hong Kong Chinese society. Their sample consisted of individuals diagnosed with Hypertension, Heart disease, Diabetes, lung disease, liver disease, kidney disease, urinary tract infections, Arthritis and Osteoporosis. They found that only Arthritis was a significant predictor of Depression in the elderly. The reason may be due to the fact that Arthritis has the potential to restrict functional capacity and is associated with chronic pain. Studies with elderly western populations found an increase in depressive symptoms in patients suffering from illnesses such as kidney and circulation diseases. This indicates that race and culture are possible factors influencing perception of disability (Bazargan & Hamm-Baugh, cited in Chou & Chi, 2002)

Depression in chronic illness seems to be influenced by various factors. Factors such as race, the severity and nature of the illness and most importantly the individual's perception of the illness may influence the incidence of Depression. Perception seems to be a function of various factors such as self-esteem, locus of control, social support and dissatisfaction of social roles.

Mood and the Progression of Chronic Illness

Various studies have explored the relationship between Depression and the progression of illness. Findings of these studies indicate ambiguous results. Some studies have supported the general view that Depression may affect the outcome of illness negatively or the chances of mortality may increase if the chronically ill are depressed. Other studies were unable to find a significant relationship between Depression, illness outcome and mortality in chronic illness.

Felker, Katon, Hedrick, Rasmussen and McKnight (2001) conducted a study to explore the effect of depressive symptoms in patients diagnosed with Chronic Pulmonary Illness. In the study with 1252 patients a significant relationship was found between reported

depressive symptoms, and poor general and pulmonary health. Patients with Chronic Pulmonary Illness and depressive symptoms reported significantly more impaired functioning and a poorer health status compared to those patients without depressive symptoms.

Lustman (cited in Pallourios, 1992) explored the relationship between Depression and glycaemic control in diabetics. The group diagnosed with major depressive episode showed poor glycaemic control compared to the non-depressive group. In Diabetes, uncontrolled glycaemic control is associated with poor illness outcome and complications.

It has been hypothesised that Depression increases mortality rates in patients with somatic disorders by interfering with immune system functioning, a patient's motivation towards recovery and by affecting compliance with treatment (Cuijpers, 2001). The hypothesis was confirmed by some studies (Colon et al., 1991; Silverstone, 1990), but other studies (Richardson et al., 1990) could not confirm the hypothesis (Cuijpers, 2001).

In a different study Cuijpers (2001) wanted to determine the relationship between mortality rates and depressive symptoms in chronically ill residents in residential homes in the Netherlands. Cuijpers found no significant relationship between mortality and depressive symptomatology in chronically ill inhabitants of residential homes. Mortality was found to be related to measures of social support as well as to the ability to perform the activities of daily living independently.

The relationship between depressive symptoms and the progression of illness and mortality is not clear. Depression may impact on illness and mortality through the immune system, metabolic control, the patient's motivation and hope, as well as his or her compliance with treatment. The ambiguous results of studies exploring this relationship may be explained by the various individual factors that affect mood such as perceived social support and quality of life. Other factors such as age, personality and the

severity of the illness may also play a role in the relationship between illness and Depression.

It may be concluded that mood and Depression seems to be a theme or a factor in understanding the impact of chronic illness on the individual. The exact nature of Depression in chronic illness is not clear. Mood and Depression may either be seen as part of the etiology of chronic illness, a factor in the outcome of the illness or part of the presentation of the illness. Other factors like perceived support, quality of life and roles may influence the relationship between chronic illness and mood and Depression.

From the literature it may be concluded that there are common themes in the experience of adjusting to chronic illness. The search for meaning, gaining a sense of mastery, the process of self-enhancement and the loss of identity are themes that were discussed as part of the adjustment to chronic illness. The relationship between mood and Depression, and chronic illness was explored. It seems that although these common themes are identified in the literature, the experience of these themes is unique to the individual with the illness. How the person perceives the illness and how he or she creates meaning from it in his or her context of living seem to be a unique experience to that individual.

The next section of this chapter explores the experience of the family living with chronic illness.

Living with Chronic Illness: The Experience of the Family

While chronic illness may have a life-changing impact on the affected individual, the experience of chronic illness may also have an influence on the individual's family.

Wiley (cited in Gregg et al., 1989) suggested that the onset of a chronic illness might be viewed as an unscheduled crisis within the structure of the family network. Families, like individuals, experience a series of developmental crises over the course of their lives. Each crisis may have an impact on the structure and the patterns of interaction among the

members of the family system. Chronic illness may be such a crisis and this may place the structures and patterns of interaction in the family under pressure. It is not only the sufferer of the illness who is forced to adopt new behaviours in relation to the family, but each member needs to adopt new behaviors towards each other as well as towards the sufferer. Chronic illness may require the family to alter or modify their structures. Families that are unable to change their transactional patterns in response to the crises of illness may become dysfunctional.

The Relational Trauma of Chronic Illness

Penn (2001) defined illness as a relationally traumatising experience, not only for the person with the illness, but for all the other members of the family as well. She used the term relational trauma to describe what happens to the family of a chronically ill beloved one. She reported on her and her colleagues' therapy with families who struggled with chronic illness and discussed the following:

Relational trauma refers to when the family members or loved ones of the ill person experience stress due to the physical and emotional hardship their loved one has to bear. In some cases the members may even develop some physical symptoms themselves. According to Penn (2001) the function of these symptoms is an expression of their anxiety and concern over their loved one. Because they do not express this and keep quiet about their own fears they may present with physical symptoms. Thus, loved ones like the affected person, may experience fear of the future, anxiety, insomnia, ruminations and many bodily complaints of their own.

Negative metaphors seem to exist in the language of illness - "dependence, poor genes, repressed personalities, weak constitutions, et cetera" (Penn, 2001, p. 39). These negative metaphors or voices may engulf the ill person and the family resulting in a silence that disconnects people at a time when connections must be relied on.

In therapy with these traumatised and silenced families, writing was used to create new voices, metaphors and multiple descriptions that may reinvigorate the conversations silenced by the illness.

Penn (2001) found that chronic illness in the family may silence the members because of a fear of speaking about what it really is like. Members become silent and experience trauma, because of the silence imposed on them by the illness.

Social Dilemma of Illness

Strong (cited in Penn, 2001) found that a person who has an illness may be viewed by society as being defective. A person is considered morally defective when he or she is ill; something must be wrong with the person – he or she is not ‘whole’ anymore. This social dilemma forces the ill to choose silence and hide their emotional life from others. Sufferers choose not to speak, but bear their illness alone. By being silent about their suffering, the ill may feel that they are protecting those whom they love from more hardship. The illness made them vulnerable - without protection - they therefore protect their loved ones from the pain they are really experiencing through their silence. Penn (2001) in her work with chronically ill families concluded that chronic illness displaces your feelings: it is as if they are stored somewhere else. The ill person may find him- or herself in a paradox of speaking or not speaking. A chronically ill person said the following:

I am afraid that if I do not speak to you and tell you how I am, I will slowly withdraw and leave you; however, if I do speak to you, I am afraid that you will slowly withdraw and leave me (cited in Penn, 2001, p. 39).

Penn (2001) has found that speaking enhances the relational connection between the members of the family, even if the connection seems to include fear, hopelessness and anger.

Narratives of Illness

Penn (2001) encouraged the chronically ill family members to express their experiences and feelings through writing. They were encouraged to write stories about the illness. The story of chronic illness is often incoherent. It is a discontinuous story, given the nature of chronic illness. The illness is unpredictable and the future hard to predict so the story may become fragmented; nonetheless, a narrative of silence and isolation is not acceptable.

Frank (cited in Penn, 2001) identified three different narratives for illness:

- Restitution narrative: “I have become ill, but everyday I am getting better.”
- Chaos narrative: Life with illness is experienced as deteriorating, falling apart and out of control.
- Quest narrative: A search for the meaning of life and illness are attempted and shared with others. Connections may be deepened or renewed.

Penn (2001) found that when family members were encouraged to speak through writing, they were able to find a narrative of meaning and deepened connections through the suffering of chronic illness.

It may be concluded that chronic illness has a profound effect on family structure as well as the relationships and connections within the family. Giving voice to the experience of chronic illness may deepen connections within the family as well as create meaning for the experience of illness.

The next section of the literature explores the experience of the health professional ‘treating’ chronic illness within the tradition of the medical model. Alternative models as well as shifts away from the medical model are also explored.

Treating Chronic Illness: The Experience of the Health Professional

Chronic illness does not only have an emotional impact on the patient and the family, but also on the health professional ‘treating’ or ‘managing’ the illness. The medical model places a high emphasis on cure. Health professionals are trained to use their expert knowledge to cure illness. However, chronic illness is not curable and is often characterised by a progression in severity of symptoms as well as a possible decline in physical functionality. The health professional has to define his or her role in dealing with chronic illness and has to come to terms with the limitations of medical treatment he or she can provide. The professional may be in conflict with his or her role as the expert and the limitations of his acquired expertise. Sweeney and Kernick (2002) stated in their plea for a more complex model in clinical practice that health professionals may be the field-workers of science and medicine (expertise), but they cannot escape their own humanity.

Who is the Professional?

Professionalism can be traced to the early part of the 19th century. At about that time people started differentiating themselves as middle class and they started to object to the European class system consisting of only the aristocracy and the proletariat. They nonetheless needed a justification for observable and necessary differences among people. Professionalism provided a solution – justification for status based on merit rather than wealth and property. A social order based on competition and ability was therefore constructed. Even today it remains the mainstay of our system of social stratification (Bledstein, cited in Baum, 2001).

Hand in hand with the status of a profession are privileges as well as responsibilities. Benveniste (cited in Baum, 2001, p. 58) describes the attributes of a practitioner of a profession as follows:

- Practitioners should be able to apply technical knowledge.
- They should have advanced education and training.
- They should have demonstrated competency and should have completed the requirements to be admitted to the profession.
- They should have the support of a professional association.
- They should be bound by a code of conduct or ethics
- They should feel a sense of responsibility to those they serve.

Wilcock (cited in Baum, 2001) however challenges the status of profession or occupation. He believes that an occupation is not necessarily a central aspect of human experience and unique to each individual. Occupations or professions may be described as the ordinary and familiar things people do everyday and therefore as such should not receive special status. It seems that the existence of occupations and professionals in society today, satisfy society's need for experts to help people do ordinary and familiar things. In other words, society assigns the status and privileges associated with professionalism to those who assist people with ordinary tasks of daily living, like caring for the ill or teaching the young.

It may be concluded that from the time of the establishment of professions, professionals have nonetheless been associated with status, privileges and responsibilities. A professional is an expert who needs to use his expertise to help people with less expertise in the task of daily living. It also seems that society has created the role of the expert professional. The challenge for all professionals is to be aware of the changing needs of society and to adapt to them (Baum, 2001). The ever increasing availability of information today may challenge the expert stance of the professional. For example, patients may have access to a wealth of information about their specific illness and are in the position to make their own informed choices about treatment. Society's needs also change in regards to who the professional is delivering a service to. This is specifically relevant for health professionals as a major shift in health care is taking place with regard to an ever increasing population of people suffering from disability and chronic illnesses (Baum, 2001). Acute illnesses may have been the focus of attention a few decades ago,

but today chronic illnesses and the care of the elderly seem to have become more relevant. These changes may challenge the appropriateness of the expert role of the healthcare professional. A more co-operative role between patient and professional would seem to be more beneficial.

The Healthcare Professional : A Helping Profession ?

Healthcare professionals, like doctors, dietitians, psychologists and occupational therapists amongst others, are viewed as helping professions as the core of the profession is to help those in need. The literature describes various theories of how help given is conceptualised by the 'helpers' or the helping professions. Truchot and Deregard (2001) explored how the medical model, from the perspective of the health professional, influences the mind of the helper. They also explored an alternative to the medical model, the compensatory model which focuses on how helpers view those who they help.

Brickman (cited in Truchot & Deregard, 2001) described the medical model as a model in which people are not held responsible for either the origin of their problems or the solution to their problems. People diagnosed with an illness may become a victim of the illness without any control over it, except for seeking the help and advice from the expert, the healthcare professional. This expert has been trained to recognise the problem and is also able to provide the treatment. Within this model the active participation of the patient is not needed for the health professional to be helpful. What is expected from the patient though, is full compliance to advice given. The patient's investment is low – the relationship within this model may be described as unbalanced. A relationship with a high investing helper or professional and a low investing, passive patient has traditionally been the relationship within the healthcare system.

An alternative to the medical model is the compensatory model (Truchot & Deregard, 2001). Brickman (cited in Truchot & Deregard, 2001) describes the model as a model in which people are not regarded as responsible for their illness, but they are held responsible for solving their problems. People in this model are viewed by others as

having to compensate for the handicaps or obstacles imposed on them by their situation with special kinds of effort, ingenuity or by collaboration with others.

The patients' responsibility is to adopt problem-solving attitudes and behaviours and to develop their potentials and skills. They must be assertive and the helper must make them aware of their own resources and inner strengths. In this relationship the patient is not passive, but a high investor, maybe even more so invested than the helper (Truchot & Deregard, 2001). Providing help within the compensatory model, where the responsibility of the illness is a shared experience between the patient and the professional may be a more rewarding experience for both.

From the discussion of the helping models it seems that the professional-client/patient relationship is determined by the model of help the professional chooses to work from. In traditional medicine the medical model is dominant. The professional as a helper takes responsibility for their patients whereas the patient seems to be a passive participant in the management of his or her own illness. How the professional perceives his or her relationship with the patient and how his or her role is determined by the model he or she chooses to work from may influence the professional's experience in treating illness.

The Emotional Cost of Helping

There seems to be an emotional cost involved for the helping professionals caring for those in need. Burnout, compassion fatigue and vicarious traumatisation are concepts found in the literature; these concepts describe the emotional trauma that professionals may experience in treating their patients.

The Burnout Syndrome

Burnout as an occupational stress outcome has been well-documented in studies on the helping professions. Burnout may be defined as a psychological syndrome, consisting of emotional exhaustion, depersonalisation and reduced personal accomplishment (Truchot

& Deregard, 2001). According to the literature exploring the causes of burnout the conclusion was made that the professional – client/patient relationship is most significant in the prediction of burnout (Truchot & Deregard, 2001).

The role of perceived inequity and communal orientation in the burnout process. Equity theory assumes that people evaluate their relationships in terms of cost and rewards. The individual will experience a feeling of equity if the ratio of his or her inputs and outcomes is equal to that of the person he or she compares him- or herself with. Inversely, in a relationship where the individual perceives that his inputs and outputs are not in proportion to the other person's inputs and outputs, he or she will perceive the relationship as unequal and may experience stress. Lack of reciprocity is an intrinsic characteristic of helping: one gives (professional) while the other (patient) receives. Professionals, especially those working within the medical model, may experience a lack of reciprocity in their relationship with their patients. Professional helpers may feel they put more energy into the relationship than their patients and may experience fewer rewards. This is the type of perception that may produce burnout in the helping professions. The nature of chronic illness may enhance these feelings of perceived inequity. This seems to be confirmed by studies which found significant associations between perceived inequity and burnout among Polish and Dutch nurses (Schaufeli & Janczur); Dutch general practitioners (Van Dierendonck, Schaufeli & Sixma) and French social workers (Truchot, cited in Truchot & Deregard, 2001).

Van Yperen (1996) hypothesised that a personal characteristic, communal orientation may buffer burnout under conditions of perceived inequity (Truchot & Deregard, 2001). Communal orientation refers to helping others on the basis of genuine concern for the well-being of other people. People high in communal orientation are more likely to help than people low in communal orientation. People or professionals high in communal orientation desire to give, are not motivated by perceived benefits, but are motivated in their desire to help others. Instead of giving benefits with the expectation of receiving a comparable benefit in return, they give with a concern for the welfare of others.

Professionals high in communal orientation may be less disturbed by perceived inequity. These professionals may be less vulnerable to burnout (Truchot & Deregard, 2001).

It may be concluded that the health professional working with chronic illness, is influenced by the model he or she is working from, his or her relationship with the patient and how this relationship is perceived as well as by personal characteristics such as communal orientation. All these factors may determine if the professional may experience trauma like burnout in the process of helping or caring for the chronically ill.

Compassion Fatigue and Vicarious Traumatization

Figley (2002) identified the concept of compassion fatigue among psychotherapists caring for the chronically ill. A similar concept, vicarious traumatization was used to describe the emotional trauma experienced by social workers in health care (Dane & Chachkes, 2001).

According to Figley (2002) compassion fatigue is defined as a state of tension and preoccupation with traumatised patients by re-experiencing the traumatic events, avoidance of reminders of the traumatic event and persistent arousal of the trauma when in contact with the patient. It is a function of bearing witness to the suffering of others. Compassion fatigue is characterised by feelings of helplessness and confusion.

According to Figley (2002) there is a cost to caring for those with chronic illness, with the realisation that these patients will never fully recover. The health professional, as a helper and a professional, needs to evaluate patients objectively and administer the best possible treatment according to the best practice guidelines. On the other hand, the professional cannot avoid his or her compassion or empathy as these are the tools of human service. Compassion and empathy imply that the professional attempts to view the world from the perspective of the sufferer. In this effort the professional may suffer. The meaning of compassion is to bear suffering. Compassion fatigue, like any other kind of

fatigue may reduce the professional's ability or capacity or interest in bearing the suffering of others (Figley, 2002).

Meier, Black and Morrison (2001) described compassion fatigue in assessing the inner life of physicians caring for the seriously ill. Among the emotions experienced by the physicians were a need to rescue the patient, a sense of failure, feelings of powerlessness, a fear of becoming ill oneself and a desire to avoid these patients.

Vicarious traumatization refers to an actual transformation of the professional's inner experience as a result of empathic engagement with clients. Vicarious traumatization and compassion fatigue, both refer to the emotional cost to the health professional in caring with empathy for his or her patients. Compassion fatigue focuses on the reliving of the patient's trauma, whereas, vicarious traumatization refers more to the long-term symptoms that professionals may experience in prolonged exposure to their patient's suffering or trauma. Prolonged and intense exposure to clients or patients may have enduring psychological consequences for the professional. Symptoms of vicarious traumatization may include emotional numbing, psychosomatic manifestations such as sleeplessness, headaches and gastrointestinal disturbances, disassociation, intrusive imagery, unpredictable emotions, and impairment of self-esteem. Through exposure to the patient's account of illness-related experiences, the professional becomes vulnerable through his or her empathic openness to the emotional and spiritual effects of vicarious traumatization (Dane & Chachkes, 2001).

From the literature it may be concluded that there is an emotional cost involved for the professional working with the chronically ill. Regardless of the model the professional follows, empathy is required in order for the professional to be effective. According to Figley (2002) empathy and emotional energy are the driving forces for working effectively with the suffering. The ability of the professional to empathise with the suffering of others is a keystone both to helping others and to being vulnerable to the costs of caring.

The Health Professional, Chronic Illness and the Future: A Way Forward?

The medical model and the alternative models discussed in this chapter do not seem to meet the needs of both the patient and the professional and therefore a different approach is required. Such an approach would not disregard the medical model and replace it with the alternative models, but would seek an inclusive model that acknowledges the needs of the patient and the professional, specifically in the context of chronic illness.

The training of health professionals as well as the practice of medicine is still strongly influenced by the medical model. In spite of this traditional way of thinking, an increasing number of articles and research have been published, questioning this paradigm, specifically with regards to chronic illness. Health professionals from various disciplines are frustrated and disillusioned with working within the medical model in chronic illness.

Sweeney & Kernick (2002) argued that the current paradigm of the scientific approach (medical model) needs to be evaluated critically and expanded to a more complex model of post-normal science. Their criticism of the scientific approach in the practice of medicine is based on three problems:

- Firstly, the scientific approach is reductionist in nature. From this point of view systems are understood by reducing them to their component parts.
- Secondly, the scientific approach relies on linearity to explain cause and effect. This means that it is understood that A causes B.
- Thirdly, the application of science to medicine has promoted a notion of intellectual celibacy – that medicine practice by the professional can be an objective scientific experiment that is presumably value-free.

Sweeney and Kernick (2002) acknowledge that patients have benefited as a result of the spectacular advances made in medicine as a result of applying the principles of science to medical practice. The scientific approach to medicine can be traced back to the thinking

of Bacon, Harvey, Newton and Descartes. The success of the scientific approach was confirmed in the 19th century by Bichat's anatomy clinic in Paris and Koch's germ theory. The scene was set for evidence-based medicine and all the developments that originated from it. The key metaphor for the body was a machine.

Sweeny and Kernick (2002) argue that science in medicine is necessary, but it is based on generalities and populations, whereas clinical practice is one-to-one individual consultations. Thus, the professional cannot only rely on his or her scientific knowledge and technical expertise, but is daily confronted with issues challenging his or her personal and moral principles. In other words a consultation in a professional's room involves more than science alone, but also the real-world lives of both the professional and the patient.

Sweeney & Kernick (2002, p. 134) published a list of paradoxes current medical practice is left with.

- *Science appears to dominate medicine, yet its hegemony is under threat.*
- *The explanatory model (medical model) is based on linearity; the natural world is non-linear.*
- *The evidence produced by the model is dichotomous: clinicians who use evidence see emerging conditions whose rate of progression remains unpredictable.*
- *The reductionist nature of the model denies the importance of the connectedness of the components.*
- *The model is presented as value free and morally neutral, but is implemented by clinicians who are not immunized from the frailty of the human condition.*
- *The scientific (medical) model does not equip clinicians for the metaphysical problems of death and dying.*

Sweeny and Kernick (2002) argue for a more complex, holistic approach as a model for clinical practice. Complexity offers the potential to incorporate the scientific approach with a firmer understanding of non-linearity and unpredictability of complex systems.

Complexity does not seek to overturn modern medicine, but to complement it by offering awareness and insight into a system's behaviour at every level. It accepts that certain activities can be described by rules, but that in many areas insight may only be obtained by looking at relationships in the overall picture. Sweeney and Kernick (2002) made their assumption from the perspective of clinical medicine, but other health professionals from other disciplines are also arguing for a more complex, inclusive model to work within when helping the chronically ill.

Baum (2002) too proposes a shift away from the medical model used by occupational therapists to a community model in their work with the chronically ill. A community model engages the patient in the process of care. The author argued that this shift would provide occupational therapists with more opportunities to help patients to function independently in their environments. In applying a community model, which engages the patient more in taking control of his or her illness, with the help of the professional, will benefit a patient in becoming less dependent on the professional and more in-charge of his or her life. The role of the professional may change from episodic care in a hospital/clinic setting to a facilitator of independent living with an illness or disability in the community.

In a study by Hall (1996) focusing on nursing the chronically ill, the use of the medical model was experienced by the patients as disempowering, dehumanising and controlling. It was recommended that the health professional in nursing must work towards maintaining a relationship with their patients, which will empower them by making them feel more connected to the world.

McIver (1999) proposed a shift from the health professional as the expert to the patient as the expert in the management of his life-long illness. The medical model is criticised for using the agenda of the professional to decide what the needs of the patient with a chronic illness are. She argues that it is very difficult for those who have not experienced a chronic illness to understand the physical, emotional and psychological demands it brings. She advocates the development of self-management programmes for sufferers of

chronic illness where they can share insights for the day-to-day management of their illness.

Bauman, Deber, Silverman & Mallette (1998) debated the role of the healthcare professional in chronic illness. They described two models in health care, namely the cure-orientated model and the care model. The cure-orientated model is traditionally embedded in the paradigm of the medical model. The care model focuses more on the specific needs of the person within his or her living context. Cure is episodic whereas care is continuous, varies in intensity and consists of a host of interdependent actions. The authors argue that these models are not mutually exclusive, but may be integrated into an approach that must be determined by the needs of the patient. The roles of which professional is responsible for what model should not be rigid, with the focus on professionals having the flexibility to move between the two different models.

From the literature it may be concluded that health professionals from various disciplines do acknowledge the successes of the medical model, but are recognising their own humanity and the changing needs of their patients. The plea is not for disregarding the medical model in the treatment of chronic illness, but for a more integrated model that acknowledges the emotional experiences of both the patient and the professional.

In this section the origin of the 'professional' as well as professionalism was discussed. It seems that society created the need for experts to help them with day-to-day living. The medical model enhanced this expert stance as well as the assumption that the clinician can be objective in treating his or her patients. This objectivity is challenged as professionals are human, vulnerable and empathic towards their patients. There seems to be a cost to caring for the ill as experiences such as burnout, compassion fatigue and vicarious traumatisation have been identified among health professionals. These experiences of the health professionals are leading to a paradigm shift away from the medical model, especially in the caring of the chronically ill. A plea for a more integrated model that involves both the experiences of the professional and the patient are recognised.

Conclusion

In this chapter the nature of chronic illness was explored. It was concluded that chronic illness is life-long with an unpredictable and uncertain course. The very nature of chronic illness forces the sufferer to go through a continuous process of adjustment to the ever-changing demands of the illness. Themes identified in the adjustment process of patients were a search for meaning, gaining a sense of mastery and self-enhancement. The experience of a loss of identity and the process of redefining oneself with illness were also described. Mood and Depression as a factor in living with chronic illness was also explored. The medical model, which is the traditional and most dominant model of the treatment of illness, mainly influenced these experiences of chronically ill patients. Alternative models, which are focussing more on the patient's experiences of illness, are also found in the literature. It seems that these models do not necessarily replace the medical model, but may be used in conjunction with it to create a more holistic understanding of the experience of chronic illness.

The chapter also described the experiences of the family living with chronic illness. Families living with chronic illness seem to experience relational trauma. Members may experience physical stress, isolation and a sense of helplessness. There seems to be a social stigma to being ill that may silence those who are ill and those living with the chronically ill. The experience of the family will not be included in this study, where the focus is on the experience of chronic illness from the perspectives of both the patient and the professional. This section was included in this chapter for the sake of comprehensiveness as the family and loved ones constitutes part of the patient's living context and therefore will affect his or her experience.

The third section of the chapter described the experiences of the professionals treating the chronically ill. It seems that there is an emotional cost involved for those caring for and treating the chronically ill. Concepts in the literature that describe the emotional trauma of the health professional are burnout, compassion fatigue and vicarious traumatisation.

The experiences of the professional seem to be informed by personal factors as well as the model within which he or she is treating the patient.

More and more professionals working within the medical model, particularly with chronic illness, have become disillusioned with the model. A plea for a more integrated model which allows for both the emotional experiences of the patient and the professional is called for.

In the next chapter the research paradigm of this study will be discussed.

CHAPTER 3

SOCIAL CONSTRUCTIONISM

Language is a labyrinth of paths. You approach from one side and you know your way about; you approach the same place from another side and no longer know your way about.

Ludwig Wittgenstein, *Philosophical Investigations*, Pt 1, Sect.203

Introduction

In this chapter, the epistemological framework for this study will be presented. Firstly, the researcher will begin with a brief explanation of postmodernism as an ontology, which prescribes the nature of reality. Thereafter, social constructionism, as the epistemological framework for this study, will be discussed. The discussion will focus on social constructionism as an epistemology as well as how social constructionism informs the present study.

Postmodernism

Scientific investigation in the 20th century has predominantly been informed by modernism. The basic assumption of modernity is that emancipation and progress can be achieved through reason and science (Kvale, 1994). The modern age made the assumption that there was a universal truth on which we could rely. The modern age searched for the one universal truth and assumed that at least some of us had access to it. Thus, in the modern era we have learned to rely on the power of science and the knowledge of objective experts who possess the truth about reality, which can be represented accurately and understood via reliable research data (Becvar & Becvar, 1996). The fact that there were thousands of people and groups, each claiming privileged access, but with no agreement on almost anything, brought such assumptions into

question (Doan, 1997). Doan (1997) states that postmodernism was ushered in when it became impossible to trust the major political, philosophical and religious root metaphors of our culture and the world at large. It became increasingly obvious that we live more in a *multi-verse*, than in any one account (*universe*). In fact, postmodernism caution us against a singular, account that claims to contain the whole truth and nothing but the truth (Doan, 1997). Postmodernism made us aware of the possibility that no one singular truth exists and that knowledge may not be objective. Postmodernism informed us that our notion of reality may be subjective. Therefore, facts may be replaced by perspectives and a multiple of realities may be equally valid (Becvar & Becvar, 1996).

This belief of postmodernism of the possibility of multiple realities informs the way research, science, language and knowledge may be viewed.

Research and science, in modernism, emphasise rationality. In modernism, plans, calculations, predictions and control are viewed as essential for scientific enquiry. People within this perspective are treated with 'objectivity' and may be regarded as objects of inquiry. A postmodernist inquiry, on the other hand will go beyond the cognitive and scientific domain of rationality by including the ethical and aesthetic domains of life (Kvale, 1994). Whereas in modernism the focus is on facts obtained in an 'objective' search, postmodernism focuses on the meaning and comprehension of a person's lived experience. The postmodernists have access to the individual person's meaning of a person's lived experience through the process of language. Therefore, language is a central theme in a postmodernist search or inquiry.

Language in postmodernism is understood as the means by which individuals come to know their world, and in their knowing, simultaneously to construct it (Becvar & Becvar, 1996). The meaning of the lived experience is created through language. Each of us is born into forms of language in a culturally created linguistic system; we learn to speak and learn to share our accounts of our experiences within that system (Becvar & Becvar, 1996). The postmodernist concerns him- or herself with these accounts, the stories people tell of their experiences in their contexts of living.

Knowledge and the power knowledge may bring to those who have access to it, is another central theme in postmodern thinking. In postmodernity there seems to be an intrinsic relation between power and knowledge (Kvale, 1994). In modernism, those who possess knowledge were given power and privileges through knowing the ‘truth’ that could be found ‘out there’ through objective inquiry (Becvar & Becvar, 1996). Postmodernism, with the acknowledgement of the possibility of multiple realities and the focus on subjective perspectives instead of objective facts, challenges the power of knowledge and asks who really possesses it.

These ideas, which underlie postmodernism, will be further explored in the discussion of the epistemology of social constructionism, which is the chosen epistemological framework of this study. Within the philosophy of postmodernism lies the epistemology of social constructionism, which guides the researcher’s thoughts and actions in the pursuit of that which may be known and understood. The principles of social constructionism and how they informed the present study will now be clarified.

Social constructionism

Social constructionism as a postmodern approach is founded on the belief that “the content of our consciousness, and the mode of relating we have to others, is taught by our culture and society: all the metaphysical qualities we take for granted are learned from others around us” (Owen, 1992, p. 386). Berger and Luckman (cited in Speed, 1991, p. 400) contend that we “socially construct reality by our use of shared and agreed meanings communicated via language; that is, that our beliefs about the world are social inventions”.

The social constructionist view supports relativism. Relativism suggests that there are parallel universes of experiences for people of different ideologies that create different realities, sets of truths, knowledge and personal experiences (Owen, 1992). Thus, social

constructionism concurs with postmodernism on the possibility of multiple realities, based on different perspectives and experiences. These different experiences or perspectives may be informed by culture and society. In this, social constructionism challenges the scientific positivistic view of truth as a description of reality (Owen, 1992). Truth, from the social constructionist view, is arbitrary depending on who is making the claim to whom and where the action occurs in time and place (Owen, 1992). Thus, social constructionism views people's, organisation's or institution's accounts of the truth within the context as well as within the relationships that may have informed their views. Therefore, science and research are not only a series of discoveries or methodologies, but a series of social constructed paradigms about sets of phenomena (Owen, 1992). According to Kuhn (cited in Owen, 1992), science is socially constructed through a process of people speaking the language of the same paradigm and over time agreeing on the same 'truths'. The social constructionist not only regards science and research as human made, but also values, ideologies and institutions (Owen, 1992). Our ideas, thoughts and actions are communicated through the process of language over time within a specific social and cultural context; within that context certain ideologies, values and 'truths' are constructed.

These values, ideologies and 'truths' are not constructed by individuals in isolation, but in relation to one another. Social constructionism supports the theme of connectiveness; people are not regarded as individuals, but connected to one another. People make sense or create meaning from their experiences through their relationships with one another (Owen, 1992).

According to Anderson and Goolishian (cited in Hart, 1995, p.184),

[w]e live with each other in a world of conversational narrative, and we understand ourselves and each other through changing stories and self descriptions.

A social constructionist perspective focuses on those narratives, which are formed by and in turn influence people. It is these normative narratives or Grand Narratives that people

measure themselves or others by (Doan, 1997). According to Doan (1997), Grand Narratives are supported by the weight of numbers, tradition, and firmly entrenched power structures. The particular meanings we impose on behaviour are dictated and organised by the dominant analogies or interpretive frameworks currently available (Becvar & Becvar, 1996). For example, whereas illness in the Middle Ages was seen as a curse or a punishment from God, illness today may be seen as a result of an unhealthy life style and not taking responsibility for one's own body.

Social constructionism concurs with postmodernism in challenging knowledge as power. It cautions against singular accounts or narratives that marginalises and silence those who have different accounts (Doan, 1997). It recognises the power of singular accounts that may subjugate people, and the power of cultural specifications and their influence on people's lives. Social constructionism also cautions those that claim to have 'expert knowledge' and therefore possess power over those who do not have access to it. It therefore prefers accounts based on a person's lived experiences rather than on 'expert knowledge' (Doan, 1997).

In the present study, sufferers of chronic illness and professionals treating chronic illness will be given the opportunity to tell their accounts or stories about their experiences within their contexts. In the sufferer / patient- professional relationship, from a modernist perspective, the professional possesses the 'expert knowledge' as well as the power within the relationship. The roles within such a relationship are also defined within the culture or society they represent.

It may be concluded that social constructionism supports the notion of the possibility of multiple realities, which are subjectively constructed through the process of language, within a social and cultural context. It cautions against singular accounts and knowledge as a vehicle of power. It prefers the stories people tell about their lived experiences rather than relying on 'expert' knowledge.

In the next section these beliefs will be explored further. The relationship between knowledge and power, and the role of language and story telling, as an expression of our experiences, will be discussed.

Knowledge is Power?

The social constructionist perspective supports the view that all knowledge, values, ideologies and social institutions are human made (Owen, 1992). These social institutions, such as the medical fraternity hold power through privileged knowledge and social constructionism challenges and critique these narratives that claim privilege and entitlement (Doan, 1997, p. 130.).

Social constructionism dares to ask the following questions (Doan, 1997).

Who stands to gain from the power wielded by this account?

Who is most oppressed by this power?

Is there room for optional stories or are they oppressed and subjugated?

Who authored this narrative? Did those most oppressed by it have a voice?

How does it recruit people into its service?

What sort of power practices does it employ?

Thus, social constructionism concurs with postmodernism in asserting that all narratives are not equally valid and in fact some narratives may abuse power through not being respectful of difference, gender, ethnicity, race or religion (Doan, 1997). However, social constructionism also recognises the role that individuals themselves play in creating and maintaining these grand narratives or institutions of power. That, which individuals may find oppressing, may be what they have created themselves.

Foucault (cited in Terre Blanche and Durrheim, 1999, p. 98) described this relationship between the individual, knowledge and power as follows:

The individual is an effect of power, and at the same time, or precisely to the extent to which it is that effect, it is the element of its articulation. The individual which power has constituted is at the same time its vehicle.

Doan (1997) agrees with Foucault (1998) that it is the individuals themselves who maintain the institutions of power. Doan (1997) uses the metaphor of the Tyrannosaurus Rex as a predator and consumer of people. We, as the people are eaten and digested by these power narratives, and we provide the fuel for their continued life. Some people unwittingly function as the claws and teeth of the 'beast' and do damage to their own kind. Our assimilation is so complete that we speak with the voice of the 'beast' and identify it as one of our own. When the oppression and recruitment is extreme, those who are most oppressed may become the most ardent defenders of the beast that has consumed them (Doan, 1997).

It seems that knowledge, from a social constructionist perspective, is different from the modernist conception of the existence of an objective, individualistic knowledge. The conception of knowledge as an objective truth has instituted itself into virtually all aspects of modern life (Gergen, 1985). Social constructionism 'unmasked' this concept of knowledge as a vehicle of power, constructed by the very same people that are oppressed by it. Social constructionism removes knowledge from the data-driven or objective domains and places it in the hands of people in a relationship (Gergen, 1985). Knowledge becomes the responsibility of people in active and communal interchange (Gergen, 1985).

In the present study, the researcher will explore the experiences of patients and professionals within the institutions of health care. Knowledge as a power vehicle and how that knowledge is constructed within the relationship between the illness, the patient and the professional may inform this study. Who possesses the 'expert' knowledge? The patient living with chronic illness? Or the professional as the expert treating the illness? The researcher is influenced by the social constructionist belief that knowledge is created

within the relationships between the patients, the professionals as well as the researcher, through the process of telling their stories about their experiences of chronic illness.

We use language to tell our stories; we use language, verbal and visual signs to make sense of the world for ourselves and communicate it to others. It is through language that knowledge is constructed in relationships and it is through language that meaning is created from our experiences. In the next section the concept of language will be explored further.

Language

Social constructionism supports the belief that the human life-world is fundamentally constituted in language (Terre Blanche & Durrheim, 1999). Therefore; a social constructionist inquiry requires a different approach from that of positivism. Positivism, a modernist approach, uses language as a window in the search of an objective reality; where as in constructionism language itself may be the object of study (Terre Blanche & Durrheim, 1999). Language helps us to construct reality through our interactions with others. Our language directs us in how we see the world and assists in generating the meaning we attached to experiences (Anderson & Goolishian, 1988). Thus, from this perspective the study of knowledge becomes the study of the performative use of language in human behaviour (Gergen, 1985).

Language, according to the Collins English Dictionary (1993) is a system of sounds and symbols for communicating thoughts. The Oxford Dictionary (1982) defines language as a vocabulary and a way of using it predominantly in one or more countries. Jordaan and Jordaan (1984) define language as a system of symbols that we use to make meaning of our world in such a way that it also has meaning for others.

From these definitions it may be concluded that language is a system of symbols or sounds, from which meaning is created in relation to others, within a specific context. The symbols and sounds will have no meaning if they were not communicated and agreed upon between individuals on what they represent. The meaning and the

representation of specific words will also depend on the context in which they are being exchanged. The word 'menopause' will in a westernised society or context, refer to a condition of hormone deficiency, whereas in a more traditional society such a word will not even exist, although woman may experience symptoms of hormone deficiency. The meaning of words and their representation may also not be separated from personal experience. Menopause may for some woman constitute a new phase in their lives and more freedom; whereas for others it may represent loss of their fertility and hence their role in society. Therefore, the context within which the meaning of lived experience is created thus becomes integral in the understanding of reality through the use of language.

Constructionist inquiry thus concerns itself with more than language as only a system of sounds and symbols, but with language as a construction of experiences in relation to others in a specific context. The constructionist view of language has been influenced by the linguistic work of Saussure (Terre Blanche & Durrheim, 1999).

Saussure introduced a fundamental difference between *langue* (the system of language) and *parole* (its use in actual situations). We are able to use language (*parole*) to mean particular things, but are always constrained in what we say by the universe of possible meanings made available to us by language (*langue*) (Terre Blanche & Durrheim, 1999).

These possibilities and constraints of language are demonstrated in a conversation between Alice and Humpty Dumpty in Lewis Carroll's *Through the Looking Glass* (Jordaan & Jordaan, 1992, p.433).

Humpty Dumpty said: "There's glory for you!"

I don't know what you mean by 'glory'," Alice said.

Humpty Dumpty smiled contemptuously. "Of course you don't - till I tell you

I meant 'there is a nice knock-down argument for you!'"

"But 'glory' doesn't mean 'a nice knock-down argument,' "Alice objected.

"When I use a word," Humpty Dumpty said in a rather scornful tone, "it means just what I choose it to mean – neither more nor less." ...

“The question is,” said Alice, “whether you can make a word mean so many different things.”

“The question is,” said Humpty Dumpty, “which is to be master - that’s all.”

Saussure (cited in Terre Blanche and Durrheim, 1999) explains this dilemma of the possibilities as well as constraints of language by describing language not only as a collection of signs of a particular concept, but as a system of meanings. Saussure pointed out that meaning of language is created through the relationships of concepts. The meaning of the word ‘woman’ is created by the virtue of standing in a certain relationship to other words such as ‘girl’, ‘man’, ‘mother’, and ‘marriage’.

Therefore, social constructionism concerns itself with language as the object of study. Language from this perspective is more than a system of sounds and symbols; language is how we express our experiences and create meaning of our experiences. It is through language that multiple realities are possible as multiple beliefs, selves and meanings may be created. It is through language that we can tell our stories of our experiences and thus make sense of the world we are living in. The stories of our society, the narratives we live by, and judge ourselves and others against, are also constituted through language. The next section will explore story telling from the constructionist viewpoint.

The Stories We Tell

Social constructionism is interested in the stories created and constructed through language that people tell about themselves and their experiences. Social constructionism prefers stories that are based on a person’s lived experience; this refers to stories that are told in the person’s own voice and are influenced by his or her perceptions and experience (Doan, 1997).

Stories or narratives refer to:

The threading together of a set of events or experiences in a temporal sequence in order to make sense of them. In most narratives there a set of characters or protagonists and plot or

through line that carries the reader or listener along. The story may be told to make a point, teach a lesson, or provide a moral exemplar. Sometimes the telling is for the sole purpose of imparting meaning. Often, in the process of telling stories to other people we create meaning for ourselves (Dean, 1998, p. 24).

Through storytelling a multi-verse of different realities may be created. Each story is the storyteller's own construction of reality, and no single story is superior to another (McLeod & Balamoutsou, cited in Rapmund, 1996).

In the present study, a space will be created so that the participants may tell their stories which reflect their perspectives and their experiences.

Social Constructionism and the Present Study

Exploring the experience of chronic illness from a social constructionist perspective challenges the researcher as concepts such as 'illness'; 'treating illness' and 'the role of the professional' in health care are very strongly grounded in a modernist perspective. Therefore, the next section will explore concepts such as illness and the role of the professional in illness from a social constructionist perspective.

Illness and Social Constructionism

Exploring illness from a social constructionist perspective challenges the conventional wisdom that medicine (diagnosing and treating an illness) is simply an empirical discipline registering what is 'out there' in nature. The question arises whether illness, widely accepted as a biological phenomenon, may be described as a socially constructed phenomenon. Various authors attempted to describe illnesses as a socially constructed

phenomenon and the next section will explore these studies as well as define illness from the perspective of the present study.

McCrea (1983) states that definitions of health and illness are socially constructed and that these definitions are inherently political. In modern times, behaviours that were previously defined as deviant, immoral and sinful are in modern times given medical meanings. For example in Victorian times the symptoms of menopause were regarded as a sign of sin and decay; in Freudian times they were viewed as a neurosis; today with the availability of synthetic hormones menopause, is described as a deficiency disease (McCrea, 1983).

Conrad and Schneider (cited in McCrea, 1983) describe these new medical meanings of our time as profoundly political in nature with real political consequences. From this perspective, medical treatments may be seen as a new form of social control. If illness is seen merely as a socially constructed concept or a form of social control, the question may arise if illness as we experience it really exists? The researcher agrees with Eisenberg (1988) who states that disorders and illness are socially constructed or shaped by the concepts physicians employ to define and classify them. Eisenberg (1988) does not imply that illness does not exist as a phenomenon in the world and is only created by people. According to Eisenberg (1988), illness does exist, forcing society to try to make sense of illness to relieve human suffering. However, the concepts society creates to account for illness come to shape not only the observations the patient and the professional make, including the remedies both prescribe, but also the very manifestations of the illness itself (Eisenberg, 1988). Eisenberg (1988) concludes that the trajectory of illness is influenced by the beliefs patients and professionals hold about the course and prognosis of the illness. Both patients and professionals are constrained by socially constructed roles. Thus, the professional is constrained in what he or she believes the meaning of the symptoms is and is constrained by the labels (medical meanings) he or she will attach to the illness. These labels will influence the professional's belief about course and prognosis of the illness. These labels will be guided by the professional's training, personal experiences and the society he or she is practicing in. The patient, on

the other hand, will also be guided by these labels, his or her belief in the expertise of the professional as well as society's view of the illness.

The present study is conducted from this perspective. Illness is seen as a phenomenon, which does exist in the world. The study does not aim to challenge the existence of illness, or view illness as merely a social construction, but is grounded in the belief that the symptoms and the suffering from illness are real. It is however the meaning of the symptoms and the experience of the illness that may be socially constructed.

In the literature illness is usually described from a modernist perspective; however, some examples of illness described from a social constructionist perspective were explored.

Culture-bound Syndromes

Culture-bound syndromes refer to illnesses that are specific to a particular culture or society (Littlewood & Lipsedge, 1987). The social construction of illness is described in the literature with examples of culture-bound syndromes. Culture-bound syndromes are specific clusters of symptoms, signs and behaviour changes recognised by members of a specific cultural group. Culture-bound syndromes may often link an individual case of ill health to wider concerns. The illness may represent symbolic meanings such as moral, social and psychological meanings for the sufferers and those around him (Helman, 1987). These illnesses or syndromes may become a way to express or resolve social conflicts and anti-social emotions within a specific culture (Helman, 1987).

Ritenbaugh (cited in Helman, 1987) conceptualises culture-bound syndromes as illnesses or dysfunctions which are characterised by one or more of the following elements:

- They cannot be understood apart from their specific cultural context.
- The etiology or origin of the illness symbolises core meanings and behavioural norms of the specific culture.
- Diagnosis relies on the technology and ideology of the specific culture.

- Treatment may only be given by participants in the culture.
- Symptoms of the illness may be acknowledged in other cultures, but are not perceived as the same illness.

Examples of these syndromes in western culture are Heart Disease, Menopause, Irritable Bowel syndrome, Ulcerative Colitis and Asthma. These illnesses are diagnosed and described from a unique westernised lifestyle and culture. The descriptions of culture-bound syndromes in western literature acknowledges the possibility of not only viewing illness from a biological perspective, but also as an expression of social meaning. Examples of these illnesses as culture-bound syndromes are discussed in the next section.

Menopause – An Illness of Deficiency?

McCrea (1983) states that in the 1960's the male dominated medical fraternity socially constructed menopause as an illness of estrogen deficiency. The discovery of synthetic estrogen redefined menopause which is a normal process of ageing, as a deficiency illness. The treatment of menopause with estrogens promised ageing women in western societies eternal youth and beauty. From a social constructionist and feminist perspective the illness model of menopause describes or dictates the social role of women in society.

McCrea (1983) identified four assumptions regarding the aforementioned that are constructed through the disease model of illness.

- Women's potential and function are biologically destined.
- Women's worth is determined by fecundity and attractiveness.
- Rejection of the feminine role will bring physical and emotional havoc.
- Ageing women are useless and repulsive.

McCrea (1983) believes that the illness definition of menopause reflects and helps to create the prevailing ageism and sexism of modern times. The ageing woman has a vulnerable status in our society. She is no longer the object of adoration and romanticism

that youthful woman are. This is usually the time that children leave home and husbands frequently seek younger partners. Physical changes taking place in her body might be compounded and negatively interpreted by the loss of her primary social role. Viewed from this perspective menopause is regarded rather as a social problem than a physical deficiency syndrome.

McCrea (1983) therefore, criticises the medical model and the western health care system for individualising the problems of ageing women as an illness and not acknowledging the social structure which assigns the ageing process of women to a maligned and precarious status.

In other more traditional cultures like African cultures, the process of ageing and menopause may be seen as natural events that do not require medical interventions. In such cultures the symptoms of menopause have a different meaning than in western culture where menopause is defined as an illness or deficiency.

Exploring the experience of illness in a specific cultural context is relevant to this study. The meaning of the illness will be explained by the patient as well as the professional within the social structures in which they occur.

Coronary Heart Disease- Expression of a Culture?

Coronary Heart Disease was described by Rosenman (1978) as the 20th century epidemic that results from psychosocial factors that are unique to the industrialised and westernised society (Helman, 1987). Coronary Heart Disease, as a culture-bound syndrome, is coloured by the belief in our society that certain ‘personalities’ are more vulnerable to illness than others.

The development of coronary heart disease has been associated with various ‘western’ factors such as smoking, obesity, high blood pressure and diet. The image of the male as an ambitious, competitive, hostile and time-obsessed individual with Type A personality

(Friedman & Rosenman, 1959), and prone to heart disease, is a familiar feature in cardiology literature (Helman, 1987). Helman (1987) explores the perception that people with Type A personality are prone to coronary heart disease as a culture-bound syndrome.

Type A personality is associated with a profound eagerness to compete, an intense and sustained drive to achieve, a continuous involvement in multiple functions, a tendency to accelerate physical as well as mental functions, and an extraordinary physical and mental alertness. If the behaviour, typical of the Type A individual results in Coronary Heart Disease, the illness may be considered cultural as it is closely linked to the individual's occupational ambitions located in western urban culture. The Type A individual seems to be both the product and victim of our modern western capitalist society. The Type A individual with Coronary Heart Disease becomes the embodiment of the values of the society as well as the contradictions between them (Helman, 1987). The Type A individual, who develops Coronary Heart Disease, is placed in a paradox by society. His behaviour is enforced by society and even rewarded, but he gets punished by developing an illness. The Type A individual with Coronary Heart Disease has internalised society's values. His or her behaviour, which resulted in illness, becomes a symbol of the core meanings and behaviour norms of the community and the wider society in which he or she lives. His development of the illness may be a solution to the paradox society has placed him in and new behaviours may develop after the crisis of a myocardial infarction. The Type A individual may become less driven and may acquire a different focus, such as better self-care and may set more time apart for leisure.

Helman (1987) concludes that exploring Coronary Heart Disease as a culture-bound syndrome does not imply that the illness is less real or aims at diminishing other views of its etiology. It, however, acknowledges that diagnoses such as Type A behaviour, or Coronary Heart Disease as a social phenomenon are unique to our culture. In the present study, the patient as well as the professional may be influenced by these social meanings and norms specific to a westernised context.

The discussion of menopause and Coronary Heart Disease as culture-bound syndromes unique to western societies informed the present study. Illnesses in these descriptions are described as real phenomena, but the meaning society attaches to illness is influenced by social structures. Culture-bound syndromes acknowledge the social component of illness. An awareness of how the social component of illness within a specific cultural context will influence the patient as well as the professional is recognised.

The present study focuses on illness within the western society as well as within a westernised health care system. The stories participants tell about their experience of chronic illness are within this specific cultural context.

The next section will explore the social role of the health professional.

The Social Construction of the Professional

The social role of the professional who treats illness has been described over the centuries in various societies. Western societies as well as primitive societies assign people to manage or heal those who are suffering from illness. The roles assigned to the healers of society will determine how they treat illness and those suffering from illness.

How society defines illness may predict the role of the professional. Turner (cited in Eisenberg, 1988) describes the social meaning of illness in the Ndembu tribe in rural Zambia. Illnesses, like all other misfortunes, were viewed as punishments from the ancestral spirits for violations of basic group norms. The role of the healer was to unmask the causes of conflict within and between tribes. The rituals were not only performed for the recovery of the ill person, but also served a preventative purpose. The healing process was performed to protect the community against further misfortune. The role of the healer in this context is described as someone who breaches the social order, enunciates moral laws and prescribes remedial action.

Eisenberg (1988) argues that this social role of the healer or health professional in modern medicine today does not differ much from what is being described in rural tribes. In western culture the definition and management of illness is also viewed as a form of social control. Health professionals may become the gatekeepers of social control by labeling people as ill. They have the social power to decide who qualifies for social programmes, benefits or pensions.

Mc Crea (1983, p. 112) in describing the role of the professional as a moral entrepreneur quotes Freidson:

Medicine is active in seeking out illness... One of the greatest ambitions of the physician is to discover and describe a 'new' disease or syndrome and to be immortalised by having his name used to identify the disease. Medicine, then, is orientated to seeking out and finding illness, which is to say that it seeks to create social meanings of illness where that meaning or interpretation was lacking before. And insofar as illness is defined as something bad - to be eradicated or contained - medicine plays the role of what Becker called the 'moral entrepreneur'.

Thus, by providing the meaning or labeling of phenomena or social occurrences as an illness, the professional gains power through his or her knowledge in treating it. Again, for example, if menopause is regarded as a natural occurrence of ageing in woman, the health professional will have no role to play; menopause as an illness clearly defines the professional's role. Therefore, by defining an illness, the role, the power and the authority of the professional is also defined.

It may be concluded that through the role assigned to the professional – diagnosing and treating illness - he or she becomes a social gatekeeper or entrepreneur. Through the role

constructed by society the professional gains a position of authority or power. Eisenberg (1988) states that once the theories that professionals advance become part of popular culture, or are directly conveyed to the patient by the authority of the professional they may shape symptoms, course and the outcome of illness.

The professional may also be constrained by the social role he or she fulfills. The cultural beliefs and the values professionals share with other members of the community may determine what professionals do and what they think they do. Health professionals, like traditional healers fulfill assigned social roles that are influenced not only by the society they serve, but also by their own professional ideology (Eisenberg, 1988).

In the present study, in addition to the experiences of the patient suffering from chronic illness, the experiences of the professional treating chronic illness will also be explored. The social role assigned to the professional will inform the experiences of both the patient and the professional.

Conclusion

Social constructionism which developed within the age of postmodernism was selected as the epistemological framework of this study. Postmodernism acknowledges the possibility of a *multi-verse* of truths and challenges the existence of one universal objective truth. Social constructionism focuses on how attitudes and ideas developed over time within a specific social and cultural context. It is especially interested in the narratives or discourses that have taken on a normative standard against which people measure and judge themselves. However, the focus of the social constructionist is the stories people tell of their lived experiences. Language, from this perspective is the tool that people use to tell their stories to create meaning and make sense of their world. Social constructionism acknowledges the power of knowledge, but challenges

knowledge, values and institutions of power as human made over time by the same society over which they constitute power.

This chapter explored how social constructionism informed the present study. The main themes of this study are the concepts of illness and the experiences of specifically chronic illness from both the perspectives of the patient and the professional. The present study is conducted from the perspective that illness is a phenomenon that does exist in the world, but how people create meaning and experience illness as well as how it is treated may be socially constructed. The roles of the patient as well as the role of the professional are constructed within a social context.

This chapter explored the epistemological principles that guided the researcher in gaining a better understanding of the experience of chronic illness. The appropriate research paradigm that is consistent with these principles will be discussed in the next chapter.

CHAPTER 4

RESEARCH APPROACH

If it (science) tends to thicken the crust of ice on which, as it were, we are skating, it is all right. If it tries to find, or professes to have found, the solid ground at the bottom of the water, it is all wrong.

Samuel Butler 2, Notebooks, 20: 'Science'

Introduction

In Chapter 3, social constructionism as the selected epistemological framework for the present study was discussed. The epistemological framework will not only impact on the nature of the research question, but also on the manner in which the research is conducted. Therefore, the research approach in this study must be coherent with the epistemology of social constructionism. Social constructionism concerns itself with the possibility of a multi-verse of realities, which are created by different perspectives and different lived experiences. These lived experiences may be presented in stories, which are created through the art of language. Qualitative research was selected as the research approach for this study as it is coherent with the epistemology of social constructionism.

In this chapter, firstly quantitative and qualitative research will be discussed in general. This will be followed by an explanation of the suitability of qualitative research in this particular study. Qualitative research as being informed by the epistemology of social constructionism will be briefly discussed. Thereafter the role of the researcher will be outlined. Finally, reliability and validity, sampling and selection, and data analysis processes will be described.

There are two basic research paradigms namely quantitative and qualitative. Quantitative and qualitative research paradigms are characterised by fundamentally different understandings or beliefs about scientific research and the nature of realities (Casebeer & Verhoef, 1997). The basic distinctions between the two approaches are conceptualised by Casebeer and Verhoef (1997, p. 2) as follows:

The word qualitative implies an emphasis on processes and meanings that are not rigorously examined or measured (if measured at all) in terms of quantity, amount, intensity or frequency. Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry... In contrast, quantitative studies emphasise the measurement and analysis of causal relationships between variables, not processes.

Thus, where quantitative research is based on positivism, describing scientific explanations through universal laws, qualitative research, in contrast, is an interpretative approach which aims at understanding social life and the meaning that people attach to everyday life (De Vos, 1998).

Descriptions of both quantitative and qualitative research will be provided in the following sections.

Quantitative and Qualitative Research Paradigms

Quantitative research relies on assumptions from the modernistic approach to science. Therefore quantitative research is usually linked to the notion of science as objective truth or fact (Casebeer & Verhoef, 1997). Quantitative research usually begins with pre-specified objectives focused on testing preconceived outcomes. When applying quantitative methods, numerical estimations and statistical inference from a generalisable

sample are often used in relation to a larger population of interest. Quantitative research is interested in demonstrating causal relationships under controlled conditions (Casebeer & Verhoef, 1997). Quantitative research is therefore defined as “the numerical representation and manipulation of observations for the purpose of describing and explaining the phenomena that those observations reflect” (Casebeer & Verhoef, 1997, p. 2). Quantitative research is therefore, a modernistic approach, whereas qualitative research is based on post modernistic assumptions. It refers to “any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification” (Straus & Corbin, cited in Golafshani, 2003, p. 600), and is instead the kind of research that produces findings arrived from real-world settings where the “phenomenon of interest unfolds naturally” (Patton, cited in Golafshani, 2003, p. 600).

Qualitative research may be described as naturalistic. Real-world, everyday life experiences are studied as they unfold naturally. Qualitative research is conducted in settings where people’s lives unfold such as their homes and neighbourhoods (Terre Blanche & Durrheim, 1999). The subjects or a phenomenon of study are therefore viewed within the social context in which they occur. Thus, a qualitative research paradigm is consistent with social constructionism which is interested in the meanings attached to the experiences within the context they occur. Therefore, the same experience may have different meanings in different contexts, which informs the possibility of a multi-verse of realities.

Qualitative research may also be described as holistic. The whole phenomenon under study is understood as a complex system, where the focus is more on complex interdependencies rather than a few cause-effect relationships (Terre Blanche & Durrheim, 1999). Thus, qualitative research is informed by an inductive process through immersion in the details and specifics of the data to discover important themes, dimensions and interrelationships. This is in contrast to quantitative research, which is deductive as phenomena are explained as facts derived from the testing of hypotheses (Terre Blanche & Durrheim, 1999).

For a qualitative researcher to immerse in the data as well as acquire meanings and discover interrelationships the researcher takes a subjective stance. Thus, the qualitative researcher does not detach him- or herself from the participants in the study, but gets involved with them in the process of exploring their lived experience (De Vos, 1998). The researcher is therefore self-consciously aware of the mutual influence his or her relationship with the participants has on the phenomenon of study. In fact participants, in collaboration with the researcher become co-researchers in creating meaning of their lived experience.

The purpose of the present study is to explore chronic illness through the lived experiences of patients and professionals. It is not the intention of the researcher to quantify these experiences seeking an objective scientific truth, but to create a better understanding of the lived experience of chronic illness and to discover underlying meanings and patterns of relationships. Therefore, the qualitative research paradigm has been selected as the research approach for this study.

Traditionally, research within healthcare is grounded in the quantitative paradigm (Casebeer & Verhoef, 1997). According to Casebeer and Verhoef (1997), the nature of chronic illness requires a broad range of knowledge and understanding to support both the quality and quantity of remaining life for the individual living with the illness. Holman (cited in Casebeer & Verhoef, 1997, p. 6) calls for a clear need for incorporating qualitative inquiry into medical research by highlighting the case of chronic illnesses.

Conventional biomedical research has not provided decisive information about the origins or management of the most prevalent contemporary medical problems, namely chronic illnesses. Finding ways to move beyond the limitations of traditional research boundaries can help expand understanding of some of the most long-term and widespread health problems facing populations today.

The researcher therefore concurs with the aforementioned plea that the nature of chronic illness requires both quantitative and qualitative research approaches to create a better understanding of living with and treating chronic illness. It is not the aim of the researcher to disqualify the wealth of quantitative research within chronic illness, but to add a different approach to create a better understanding of the complexity of chronic illness.

It may be concluded that as the qualitative research paradigm allows for the possibility of a multi-verse of realities; acknowledges the social contexts from which meaning is created; includes the subjectivity of the researcher and embraces the relationship with participants, it is consistent with the epistemological principles of social constructionism.

The choice of an appropriate research paradigm is not only based on the suitability of its methodological techniques but also on its fit with the epistemological framework of the study. Social constructionism was chosen as the epistemological framework for the present study, which is coherent with a qualitative research paradigm. Social constructionism, as an epistemology was fully discussed in Chapter 3 and its specific application to this research study will be discussed in the following section.

Qualitative Research and Social Constructionism

Social constructionism is coherent with a qualitative methodology. The basic tenets of social constructionism as described in Chapter 3 may be summarised to include the following:

- The possibility of a multi-verse of realities, which is created by different perspectives and different lived experiences.
- These multi-verse of realities are informed by culture and society. In other words, our experiences and perspectives are shaped through the contexts in which they occur.

- We attach meaning to our experiences in our relationships with others through the process of language.
- Through language we may tell our stories of our lived experiences to create meaning and make sense of our world. Thus, realities may be co-created through sharing our stories with others within the contexts we live in.

In this study, the participants will share their stories of their experiences of living with and treating chronic illness, with the researcher. In telling their stories, meanings may be co-created through the dialogue between researcher and participants. The dialogue that takes place in the interview, is referred to as the research context. The researcher as well as the participants brings their own realities into the research context. The researcher aims to understand the participants' worlds from their perspectives, which will be informed by their social contexts, culture and experiences. The researcher tries to listen and reflect on the main themes within the dialogue. In the dialogue between the researcher and the participants, the researcher may share and reflect on the meanings of the participants and therefore different meanings may be co-created. Thus, coherent with the qualitative research paradigm, the researcher does not take an objective stance, but influences the research and is influenced by the research. The role of the researcher and her relationship with the participants will be explained in the next section.

Role of the Researcher

In keeping with the qualitative research paradigm, the researcher does not take an objective stance with regard to the research topic or the participants. The qualitative researcher does not suppress his or her traditions, history or personal views, but acknowledges them in the way that they could colour his or her own interpretations of the data collected (Mc Bride & Schostak, 2005). In a qualitative study, the researcher will reflect on his or her own views and will make this known to allow the reader of the study to judge the biases and position of the researcher (Mc Bride & Scostak, 2005). Thus in qualitative research, we cannot explore and understand other people's experiences without acknowledging the influence of our own. Mac Intyre (cited in Mc

Bride & Stostak, 2005, p. 5) refers to the relationship between the researcher's own views and the research as follow:

There is no way to engage with or to evaluate rationally the theses advanced in contemporary form by some particular traditions except in terms which are framed with an eye to the specific character and history of that tradition on one hand and the specific character and history of the particular individual or individuals on the other.

However, the researcher in acknowledging the influence of his or her own views also needs to bracket them in the sense that he or she does not allow them to dominate the interpretation of the stories of the participants. Interpretation may result as a co-creation of influences between the participants and the researcher, but not an interpretation dominated only by the experiences of the researcher.

In other words, how researchers describe what they see indicates their belief system which may direct their actions. Thus, the research says as much about them as about their participants. The researcher and the participants are both active participants in the research process as each one brings to the research context their own experiences, history, views and traditions (Rapmund, 1996). The relationship between the researcher and the participants will also influence the research, the participants and the researcher. Bopp and Weeks (cited in Rapmund, 1996) view the research situation as a function of the researcher and the participants, as well their relationship.

The purpose of research should be clearly stated before the research project is commenced. In this study the researcher informed participants that the researcher was conducting research on the experience of those living with chronic illness as well as the experience of those treating chronic illness. The aim of the researcher was to create a better understanding of chronic illness from the different perspectives of those living with and those treating chronic illness. The two groups of participants, the patients and

the professionals, were aware that the research would include both perspectives. This study would give them the opportunity to tell their stories about their lived experiences. She explained to them that the majority of research on chronic illness has been done from a modernistic perspective, focusing on the specific illness and not necessarily on the person living with or treating the illness. The focus of this study was the personal experience of the illness and the impact on each participant. She also expressed the hope that in sharing their stories and reflecting on their experiences the meaning in their suffering could be created or that possible new meanings could emerge.

At the outset of this study, the researcher described her role as researcher to her six participants. Her interest in chronic illness was both personal and professional. Being born with a congenital defect of the bowel she had extensive surgery as a child and as a result experienced life-long related symptoms. The researcher qualified as a dietitian and has been actively working with chronic illness for more than 15 years. In the process of advising patients with chronic illnesses such as Diabetes, it struck her how the traditional medical training emphasises illness and not the person with the illness. She decided to pursue a second career, this time in Psychology and began to question her 'expert' position as a health professional – who is really the expert, the person with the theoretical and scientific knowledge or the one living with the illness? These questions motivated her to explore chronic illness from the experiences of the patients, but as a professional she is also aware of the limitations of training and the personal impact of treating people with illness and therefore included both the voices of the patients and the professionals in an attempt to reach a better understanding of the complexity of chronic illness. At the time of conducting this study, both the researcher's mother-in-law and father-in-law were diagnosed with Lung Cancer and Leukemia respectively. This experience, as a member of a family living with an illness such as Cancer at the time of the research made it very personal for the researcher. Participants were made aware of her personal and professional interests.

Concurrent with her contact with the participants, the researcher conducted an extensive literature survey on the subject of chronic illness, the impact of chronic

illness on the individual as well as significant others, and the role of health professionals in chronic illness in an ever changing health care system. These readings and other researcher's opinions on the subject of chronic illness also contributed to the researcher's perceptions.

Reliability and Validity

Reliability and validity are strongly rooted in the positivistic perspective of quantitative research. In quantitative research reliability refers to the "degree to which a measurement, given repeatedly, remains the same and the stability of a measurement over time and the similarity of measurements within a given period" (Kirk & Miller cited in Golafshani, 1983, p. 598). Validity determines whether the research truly measures that which it was intended to measure (Golafshani, 2003). Reliability and validity should be coherent with the research paradigm as well as the chosen methodology and therefore needs to be redefined in qualitative research. According to Golafshani (2003) reliability in qualitative research essentially refers to the evaluation of the quality of the research. In qualitative research, quality will refer to how the study fulfilled its purpose of "generating understanding" (Golafshani, 2003, p. 598). Therefore, reliability in qualitative research may refer to the trustworthiness, credibility and dependability of the study. One of the strategies to achieve this is disclosing the steps of the research and verifying it through examination of such items as raw data, data reduction products and process notes (Campbell, cited in Golafshani, 2003).

The concept of validity in qualitative research may be described in a wide range of terms. According to Winter (cited in Golafshani, 2003, p. 602) validity, in qualitative research is not a single, fixed or universal concept, but "rather a contingent construct, inescapably grounded in the processes and intentions of particular research methodologies and projects". Thus, validity may be affected by the researcher's perception of validity in the study and is guided by his or her choice of paradigm. Validity in qualitative research may be redefined in terms such as quality, rigour and trustworthiness (Golafshani, 2003). One of the strategies that qualitative researchers

may use to ensure validity is triangulation. Triangulation refers to information from multiple data sources, multiple data collection and analysis methods, and/or multiple investigators (Stiles, cited in Rapmund, 1996).

In this study the researcher aimed to achieve reliability in the following ways:

- The researcher will disclose her orientation.
- The social and cultural contexts of the participants, as well as the researcher, will be made explicit through the stories told.
- How the investigation affected the researcher is made explicit through her descriptions of her own personal reflections. Difficulties that she might encounter and how the themes enriched and extended her understanding of the complexity of living with and treating chronic illness will be discussed.
- Reliability will also be achieved through the process of iteration. The researcher will dialogue with the text which will include audiotapes and transcripts. She will listen, read, conceptualise, re-read, reconceptualise and her observations will change and evolve in the process (Stiles, cited in Rapmund, 1996). Interpretations will be grounded by linking them to excerpts from the original text and the context in which they occurred.

In this study the researcher aimed to achieve validity in the following ways:

- Validity will be achieved through triangulation from multiple data sources or perspectives which refers to the different voices of the patients, the professionals and the literature to create an understanding of the experience of chronic illness. Coherent interpretations which fit with the experiences of both participant groups and their worlds will be offered.
- Validity may be achieved in the hope that the study will enrich and extend the understanding of the complexity of chronic illness for the readers of the research.

- In the process of seeking meaning or interpretation the researcher's interpretations will keep on evolving and changing as she continues to reflect on the data.

Sampling and Selection

Sampling refers to the process of selecting participants to include in the research study (Terre Blanche & Durrheim, 1999). A quantitative research paradigm dictates sampling procedures which are representative of the specific parameters from which the research conclusions are drawn. In other words, samples of participants are drawn in terms of the criteria of how representative they are of the parameters that are being studied. In a qualitative research paradigm, on the other hand research participants who are able to provide rich descriptions of the experience that is being studied are selected. Therefore, qualitative research, which is "less concerned with statistical accuracy and more concerned with detailed and in-depth analysis, typically does not draw large or random samples" (Terre Blanche & Durrheim, 1999, p. 45). Researchers prefer to look intensively at a few cases where individual differences and context are highlighted (Rapmund, 1996).

In this study, sampling was purposive and convenience selection was used. Participants were selected who could provide rich descriptions of the subject under study.

The sample comprised of two groups: Three individuals (patients) living with chronic illness and three health professionals working with chronic illness. The selection of the two groups will be discussed separately.

Individuals Living with Chronic Illness

The participants selected, were two females and one male, each living with a chronic illness for a period of more than a year. Chronic illness is distinguished from acute illness as being life-long and therefore it was important for the researcher to include participants who have been living with the illness for an extended period of at least a year.

Gloria is a fifty year old female, living with Insulin-Dependent Diabetes for more than ten years. Diabetes is a chronic illness, which requires daily control through a specific diet regime and insulin injections. Diabetes, if uncontrolled, is associated with complications such as heart disease, kidney failure and deteriorating eye sight.

Pamela is a thirty seven year old female, who was diagnosed with a severe form of breast cancer three years prior to the research study. Breast Cancer is a life-threatening illness and when diagnosed is treated with chemotherapy, radiation and/or surgery.

Dick is a male in his mid-fifties, suffering from Chronic Fatigue Syndrome. Chronic Fatigue Syndrome or 'Yuppie Flu' may be diagnosed through the detection of the Epstein Barr virus in the blood and leads to symptoms such as severe chronic fatigue and burn out.

The researcher included individuals with different illnesses in the sample as the aim of the study was not to explore the impact of a specific illness, but the unique and individual experience of living with an illness that is not curable and is life-long.

The Health Professionals

The researcher included professionals working with chronic illness from different disciplines. All health professionals are trained from a modernist perspective within the medical model, but different disciplines focus on different aspects of an illness and of

health care. Including different professionals added more and richer perspectives to the complexity of treating chronic illness.

Dr. P is a female medical practitioner with more than twenty years experience. She has vast experience in working with trauma, HIV-AIDS, Cancer and other chronic illnesses.

Sharon is a matron at a care facility for the chronically ill. Patients are admitted permanently to this facility as their illnesses are at such an advanced stage that they are no longer able to care for themselves. Sharon has been nursing the chronically ill for more than eighteen years.

Carin is a dietitian in private practice and is mainly working with patients who require lifestyle changes to control their chronic illnesses such as Diabetes, Heart Disease and Hypertension.

The researcher was put in contact with the participants through various sources. The researcher is actively involved at a dietetic practice in a medical clinic. Gloria, as a patient of the clinic was asked to be involved in the research study. Dick was referred to the study by another professional at the clinic. Pamela was referred by a friend of the researcher. Dr. P and Carin are practising at the clinic and were asked to participate by the researcher herself. Sharon was referred to the study by Dr. P.

Written consent was granted for the study by the managers of the health care group who own the participating clinics.

Participants were asked if they would be willing to participate in this study. They were either contacted personally or telephonically and the process and purpose of the research were explained to them. All participants agreed to take part in the study.

The researcher obtained the written consent of participants to tape record sessions and to use the information solely for the purposes of research.

Data Collection

The interview was the method used to obtain information. An interview may be defined as an interaction between two people, the interviewer (researcher) and the interviewee (participant) (Kvale, 1983). The interview within the qualitative research paradigm according to Kvale (1983, p. 173) is the context “where ordinary people are able to describe their own life-world, their opinions and acts, in their own words”. The purpose of the qualitative research interview is to gather “descriptions of the life-world of the interviewee with respect to interpretation of the meaning of the described phenomena” (Kvale, 1983, p. 173). The qualitative research interview may be viewed as semi-structured as it is neither a free conversation nor a structured questionnaire (Kvale, 1983). In this study, questions asked were open-ended but focused on certain themes around the experience of chronic illness. The interviews were taped and transcribed word for word. Both the tapes and the typed text formed the data which were used.

The interview may be defined as an interpersonal situation, where the researcher and the participant react in relation to each other and reciprocally influence each other (Kvale, 1983). In this study, the participants were encouraged to tell their stories focusing on the theme of either living with or treating chronic illness. The ‘patient’ group was encouraged to tell their life stories in the context of being chronically ill. The interviews with the professionals focused on two levels, firstly, their professional experience and secondly their own experience as a person and not as a professional within the context of working with chronic illness.

The interview was flexible and adapted to each individual’s situation. Two interviews were conducted in Afrikaans and the other four in English to accommodate language preferences. The role of the researcher was to listen carefully and reflect on the meanings that she understood from the interaction with the participants. In other words,

through the process of interaction between the researcher and the participants, meanings were co-created through language.

Method of the Interview

An in-depth interview was conducted once with each of the six participants. In the case of the 'patient' group, information on the illness, diagnosis of the illness, the impact thereof on their identity, their roles within their family system and society, their future with illness, feelings experienced of being ill and the meaning they attached to the illness were obtained. The interviews with the professionals focused on themes such as coping, training, roles and expectations of patients, as well as on their personal experiences and relationships which influence their choices as a professional.

Data analysis

Data analysis refers to the process whereby order, structure and meaning are imposed on the mass of data that is collected in a qualitative research study (Rapmund, 1996, p. 119). In this study the researcher used thematic analysis as an interpretive approach to data analysis. Thematic analysis as a qualitative data analysis method falls within the tradition of hermeneutics.

Hermeneutic human sciences study the objectivations of human cultural activity as texts with a view to interpreting them, to find out the intended or expressed meaning, in order to establish a co-understanding, or possibly even consent; and in general, mediate traditions, so that the historical dialogue of mankind may be continued or deepened (Radnitzky, cited in Kvale, 1983, p. 185).

In other words hermeneutics is a study of the interpretation of texts, where the purpose is to obtain a valid understanding of the meaning of a text. The interpretation of meaning is characterised by a hermeneutic circle. In an attempt to describe the application of the

hermeneutic cycle in the analysis of the qualitative research interview Kvale (1983, pp. 186/187) identified the following phases in the process of the interpretation of meaning.

- The first and second phases involve the immersion in the data obtained, through a back-and-forth process between parts and the whole. Thus, starting from a vague and intuitive understanding of the text as a whole, its different parts are interpreted, and out of these interpretations the parts are again related to the totality. The researcher will first read the interview to get a more general understanding or meaning. This will be followed by re-reading in an attempt to identify certain themes and special expressions. The researcher will attempt to develop meaning from the themes identified and then return to the global meaning of the interview. The process may repeat itself until the researcher feels that the cycle of interpretation is exhausted or complete. In other words the interpretations in an interview will stop when the meanings of different themes in the interview make sensible patterns and form a consistent unity.
- The third phase is the ‘testing’ of the part-interpretations against the global meaning of the text. This implies a comparison of the interpretation between the different statements and the global meaning of the interview and/or other information or statements about the interviewee.
- The fourth phase refers to the ‘autonomy of the text’ implying that the text should be understood on the basis of itself, by explicating what the text itself states about a theme. The aim of the analysis is an attempt to understand what the interviewee is expressing about his or her life-world. The analysis must be a reflection of what the person is expressing about his or her world. In other words the interpretation of the researcher may represent a deeper understanding of the life-world of the interviewee. However, the interpretation needs to be true to the story of the interviewee.

- The fifth phase involves ‘knowledge about the themes’ of the text. The interpretation of the qualitative research interview requires an extensive knowledge of the themes of the interview in order for the interviewer to be sensitive to the different nuances of meaning and the different patterns that may be identified. However, themes emerge from the text and cannot be predicted in the sense that the researcher will know beforehand the themes of the text, but the interview may evolve around specific themes related to the experience that is being explored. The researcher’s knowledge of the experience may help him or her to be more sensitive to possible meanings and patterns that may emerge from the interview or text.
- The sixth phase involves the awareness of the researcher about his or her own presuppositions in the whole interpretations of the text. The interpretation of the meaning of the text requires an understanding by the researcher of his or her own “tradition of understanding he or she lives in” and how it influences the meaning created from the text (Kvale, 1983, p. 187). Therefore, the interpretation of meaning requires from the researcher to be explicit about his or her presuppositions which must be taken into account during the process of interpretation.

Kvale (1983) also states that every interpretation involves innovation and creativity. The interpretation of a text or an interview may imply “enrichment, an extension, of the meaning of the themes which were focused upon” (Kvale, 1983, p. 187).

The phases and principles described by Kvale (1983) do not involve a formalised technique or a systematic methodology, as the existence of a specific method in hermeneutics is debated within the literature. However, the phases described are viewed as an “explication of an approach to analysis of human life-world and interpretation of texts” (Kvale, 1983, p. 188).

The following steps which are linked to the context of the aforementioned practices were executed in this study:

Step 1: The taped interviews were transcribed.

Step 2: The researcher carefully listened to the tape recordings while simultaneously reading the transcribed interviews. The transcribed interviews are to be found in Appendix (ii) and Appendix (iii).

Thus far the analysis was mainly on a content level. The analysis then moved to the interpretive level, the level of meaning.

Step 3: The researcher carefully read and re-read the original transcriptions and identified patterns and themes, which were relevant to the research context. The research context in this study refers both to the experience of those living with a chronic illness and the experience of those treating chronic illness.

Step 4: The researcher then provided an analysis of the themes identified for both groups. The description of the themes portrayed was divided into two separate discussions – themes identified from the ‘patient group’ and themes identified from the ‘professional group’.

Step 5: The discussion of the analysis of the themes identified for the two groups was followed by a comparative analysis of links between the themes identified in this study and the relevant literature.

Step 6: The researcher, in the process of identifying themes, was consciously aware of the impact of her relationship on the interviews with the participants as well as how her professional and personal history coloured her observations. To make this known to the reader, the researcher described her personal reflections as part of the analysis of the data.

Step 7: In the concluding chapter, this study is evaluated and recommendations for clinical practice and future research proposed. An integration of the themes of the two participant groups was provided in the concluding chapter, along with guidelines for a collaborative patient-professional relationship in the context of chronic illness.

Conclusion

In this chapter qualitative research, as the research approach of this study, was discussed. The nature and the complexity of chronic illness require a better understanding of the illness experience as it progresses over time. To create a more enriched and extended understanding of chronic illness this study gave patients, living with chronic illnesses the opportunity to tell their stories about their experiences, situations, problems and lives. The experience of illness lies within the context of health care and the medical world, and therefore to create an understanding of the complexity of illness, the voices and stories of the professionals were included in this study. This research does not claim to be the ‘only true description’ and does not aim to give explanations or theories regarding the experience of chronic illness. However, the information elicited in this study may help us to understand the complexity of the experience of chronic illness, exploring it from the different perspectives of the worlds of the patient and the professional.

The next chapter will focus on the analysis of the interviews with the patients living with chronic illness. Themes identified from these interviews will be explored.

CHAPTER 5

THE VOICES OF THE PATIENTS

*Ulcers and the dung-heap were necessary before Job
could receive the revelations of the world's beauty.
For there is no detachment where there is no pain.*

Simone Weil Gravity and Grace: 'Illusions'

Participant	Pamela
Age	37 years
Marital Status	Married with one child
Occupation	Sales and Marketing Manager
Illness	Breast Cancer currently in remission
Onset of Illness	Three years ago (2002)

Participant	Dick
Age	Mid Fifties
Marital Status	Married with adult children
Occupation	Owner of an insurance company
Illness	Chronic Fatigue Syndrome
Onset of Illness	Eighteen months ago (2004)

Participant	Gloria
Age	Early Fifties
Marital Status	Married with two children
Occupation	Housewife
Illness	Insulin Dependent Diabetes
Onset of Illness	Ten years ago (1994-1995)

Introduction

This chapter will explore the main themes related to the patients' experiences of living with a chronic illness that emerged from the texts. The themes identified from the experiences of the professionals will be discussed in the next chapter. The transcripts of the three interviews (texts) are attached in Appendix (ii).

It needs to be noted that the themes that were identified are coloured by the lens through which the researcher interpreted the stories of the participants at this point in time. Therefore, these themes do not claim to represent the only truth for these participants, but are possible interpretations emerging from the perspective of the researcher. The themes identified in this chapter are not exhaustive as another person may highlight different or additional themes.

The themes highlighted in this chapter seem to be central to the experience of living with a chronic illness. The participants in this study were diagnosed with different illnesses and were interviewed at different stages in the progression of their illnesses. This impacted on their different experiences and made each story unique as described in the following metaphors.

Pamela, diagnosed with Breast Cancer commented:

*Ek probeer vasgryp aan lewe en dit het vir my gevoel of ek sand
gryp en ek kry dit nie in my hand vasgehou nie.*

Pamela's metaphor represents the total shock and disbelief and the feeling of 'drowning' and reaching out for some substance when she was confronted with a life-threatening illness at the age of thirty seven.

Dick living with Chronic Fatigue Syndrome said:

.... It is just another development in how to manage myself; at that stage I was managing myself to run an office, now I need to manage myself to... (cope with this illness.)

Dick's metaphor seems to represent him as the businessman and manager. With the same goal-orientated attitude that made him a successful executive he was determined to manage the diagnosis of a chronic illness.

Gloria suffering from Diabetes said:

It was just an irritation that came along, like a thorn in one's side. A thorn you could pull out, this remains.

It is a heavier handbag, that is all.

Gloria's metaphor seems to illustrate how she incorporates Diabetes into her life. She never ignores it, but never allows it to impact significantly on her life and 'carries' her illness through life as an accessory.

Although some themes appeared to be present in all three stories and will be discussed in the next section, there was uniqueness in every story emerging from the difference in type and severity of illness and each participant's own perceptions and attitudes towards life.

Fear vs. Defiance

When a patient is diagnosed with a chronic illness it is often accompanied by fear. Losing one's health is often associated with the fear of losing one's physical abilities. For the participants in this study, their diagnoses of a chronic illness and having to live with it were associated with fear; not only the fear of possible life-long physical disability, but fear in various other spheres of their life. However, this fear did not necessarily immobilise them, but was met with defiance. Participants were defiant in refusing to allow this fear to control them or the illness to destroy them, not only physically, but emotionally as well.

Fear of the Unknown

The nature of a chronic illness is unpredictable and therefore it seems that when the illness is suspected and/or diagnosed the initial reaction is of fear of the unknown.

In Pamela's case it seemed that after discovering the lump in her breast she was confronted with the possibility that she may have Cancer. The Cancer at this stage was not yet diagnosed, but she suspected it and feared the possibility of having Cancer, in other words she feared the unknown. She describes this feeling as follows:

Ek was bekommerd ek het nie presies geweet waarom nie, maar iets het my gepla...

...daar was oomblikke wat ek alleen was wat dit my onsettend bekommer het, so ek het daar buite gesit gaan eenkant sit en gaan huil en gewonder wat as dit erg is?

Dick was also confronted with the unknown, when his doctor asked him to come and see him to discuss his blood results. He said:

I didn't really know what to think, I did not know what to think, I did not know...there was obviously a concern.

...obviously one is very concerned when you get a call that say doctor want to see you because of blood results.

Gloria, on the other hand did not experience feelings of fear at the stage of diagnosis, as she felt that it was possible to control her illness. She did, however experience fear as the illness progressed over time. In spite of all her efforts to be compliant with the treatment regime and despite the reassurances of her doctor, the progression of the illness was still unpredictable and uncertain and there was a part of her that did experience fear of the unknown of what lay ahead. Gloria said:

I said I hope you(the doctor) are not lying to me, I hope that I am doing all this right and I am getting results, if something goes wrong with my kidneys, I swear to God...

It seems that this fear of the unknown when one suspects a chronic illness and the fear that accompanies the diagnosis of a chronic illness emerge from its unpredictable nature. Despite all the advances in medicine and all the available treatments, the progression of chronic illness is unpredictable and uncertain, which leaves its sufferers with possibly a feeling of not being totally in control. This feeling of powerlessness to control the illness may institute fear when one suspects and is diagnosed with it..

Fear for those we Love

Being diagnosed with a chronic illness and having to live with the illness, not only impacts on the sufferer, but also on his or her loved ones. The fear experienced by the participants, as a result of the diagnosis and its possible consequences, was not only for their welfare, but also included their loved ones. A theme of fear for those we love emerged from the participants' stories. It seems that an illness leaves one unprotected and therefore we want to protect the ones we love. In other words, the sufferer seems powerless to control the illness and therefore feels vulnerable, not only in themselves but also for their loved ones.

When Pamela was diagnosed with Breast Cancer, which can be fatal, seeing her husband's pain and being concerned about her young daughter were more than she could bear. She said:

...maar die aand toe ons gaan lê toe sien ek my man... die trane loop so oor...toe weet ek. Dit het my dit was... ek dink van alles was dit al klaar vir my die ergste, op daai punt...

Ek is nog so jonk, daar is nog so baie dinge wat ek wou gedoen het, jy weet, hoe, wat van my kind, dis al, die meeste wat my vreeslik gepla het.

A sufferer of Chronic Fatigue Syndrome is plagued with total exhaustion at times which forces him or her to withdraw from normal activities like going shopping, eating out and visiting friends. Dick was concerned that the debilitating effect of the illness on him was impacting on his wife. He said:

It must be very, very difficult for her, because there is nothing you can see, you know from it...

Thus, the fear not only emerges from the illness and its consequences, but also touches other aspects of the participants' lives, such as their concern for loved ones.

The etiology of Diabetes is unclear, although it is believed that a genetic factor may be present in its onset. Therefore, Gloria feared that her children might become diabetic if it was found to be hereditary. Gloria said:

I would not mind knowing why, but you know ten or twelve years down the line it does not really matter, does it? If it were genetic, I would worry about my children.

Fear of being Labeled or Judged

It seems as if a diagnosis of a chronic illness is accompanied by a fear of being labeled or judged. The person affected feels that the diagnosis will change people's perceptions of who they are and their abilities.

In the case of Pamela she did not allow others to see her pain, as she did not want to be labeled as 'depressed' as it did not fit with the persona that she portrayed to the outside world. She said:

En mense het gekyk na my, omdat ek nooit, nie nooit nie, maar hulle het nie die depressiwiteit of daai emotionele 'breakdown' kant van my gesien nie, want elke keer as hulle met my gepraat het, het ek elke keer sterk gewees en gesê dit gaan goed en

opgewonde, vriendelik gewees en so aan. Ek dink hulle was 'amazed'.

Ek dink my man was eintlik wat my, ek kan nie onthou dat ek so baie met hom gedeel het nie, ek dink daar is 'n kant van my, wat hy 'even' nie bewus was van nie...

Ja, soos wat hulle my sien wou ek ophou. Daai front wou ek ophou en nie laat gaan nie. En vir myself, want dit is hoe ek myself sien. Daai persoon, sterk en in beheer. Ek ken die Here, ek wou nie toelaat dat mense dalk sien 'O nee, sy verloor dit dalk heeltemal nie'.

This fear of being labeled or judged silenced Pamela. She was not able to share her fears and her real feelings about her illness with others.

Dick felt that as Chronic Fatigue Syndrome is not a visible illness, and is not even recognised by some experts in the medical fraternity he was, therefore afraid to share it with others, who might find him boring if he talked about his illness. He said:

...the most difficult thing about the whole thing is that outwardly without exception of extra rings under your eyes, because you are so tired there is no outward sign that there is anything wrong, so the boredom that you see coming from people who don't have it or don't understand it you just tend to say nothing to them.

Like Pamela, he too retreated into silence, erecting walls so that no one could see in.

Gloria felt that the diagnosis of diabetes is often met with preconceived ideas which she perceives as negative. She had the following to say:

...and nobody knows I am diabetic and the first thing, she turn around and said to me – 'Is he diabetic?' and I said 'No, what has that got to do with anything?' 'Oh, you know diabetics got mood swings' And I thought this is so typical, you know, I was with, when I was diagnosed my kids were still at school and I was lift clubbing, lifting with another woman and I did not want to tell her, because they think you are going to have fits at the wheel of the car and blackouts and maybe some people do, but it

is this negative attitude if you are a diabetic, when you do something strange – cause she is diabetic.

Yes, because you are diabetic and you sitting with a fat milkshake and they look at you- you should not be eating that or why not, because you are diabetic...

...My gym instructor does not know I am diabetic, I will never tell him, because he will start saying – oh you better do not this...

Gloria's perception of how other people view diabetics also silenced her. Perhaps the silence freed her from having to cope with the negative perceptions others have about Diabetes. She has been a well controlled diabetic for years and very few people actually know.

Thus, fear of being labeled or judged seems to be accompanied by a collusion of silence. It seems that the participants as a result of this fear set up rigid boundaries in the sense that through their silence they maintain a façade and do not allow others in. This might be seen as a coping strategy in protecting their identities.

Fear of Physical Disability

Chronic illness is associated with physical disability. Symptoms may be experienced as under control, but over time new symptoms or complications as a result of the progression of the illness may present themselves.

Fear of physical disability as a consequence of the illness also emerged from the participants' stories.

In the case of Pamela, she was diagnosed with severe Breast Cancer and she was afraid of dying. She said.

...jy weet nie hoe vorentoe nie jy weet nie wat lê vir jou voor...dit voel amper asof jy klaar jou tassie moet pak en wag vir die dood.

Pamela also feared the physical side-effects that the treatment might cause, such as nausea and the loss of her hair. She commented as follows:

...daarvoor (chemotherapy) was ek net ongelooflik bang, want ek is vreeslik bang vir naarheid, ek is vreeslik bang vir dit, meer as enigiets anders.

Dit was scary- ek wou ...oe ek wou dit nie toelaat nie. Want 'even' toe die dokter vir my sê ek gaan deur chemoterapie gaan ... en ek dink ek gaan my hare verloor, ek gaan altyd siek wees...

It seems from the story of Pamela, that the sufferer not only fears the illness and its outcome, but is also scared of the treatment offered. The possibility that the treatment that is supposed to 'cure' you can also make you ill, seems to be frightening. The possible physical changes, that might result from the treatment, like losing your hair, is also met by fear. It may be argued that losing your hair to save your life is a small price to pay, but losing your hair and having your appearance change may challenge your identity and may be experienced as a great loss. Fortunately, Pamela did not have to undergo chemotherapy, but was treated with surgery and radiation instead.

Gloria feared the possible complications of Diabetes, such as kidney failure and the possibility of having to have dialysis at some stage of her life. In contrast to Pamela, she was not afraid of dying, but afraid of living with the debilitating effects of the complications of her illness.

I would not, I would just take a huge overdose and that would be that. I made that decision a long time ago, if something like that happens, I would just end it, because I don't see any point, because the end is near, so to speak and what sort of quality of life you've got –zilch, so I would not deal with that.

It seemed that in order to contain her fear, she had an end point in sight for herself. She would not allow her illness to take absolute control over her life; instead she would use the control she still had even if it meant ending her life.

It seems that in spite of all the fear that an illness brings, the sufferers fight back. They become defiant and protect what is meaningful to them, such as their identity, self-image, roles and way of life. Defiance was a further theme that emerged from the stories of the participants.

Defiant in Keeping Identity

Pamela was so defiant in keeping her identity as enthusiastic, friendly and in control that she refused in the midst of cancer to become a victim, and instead became a rescuer. She said:

Ek het myself gekenmerk of 'n 'label' op myself gesit as entoesiasties. Jy weet, dit is so, dit is baie moeilik om jou saak mee tred te hou, maar ek dink jy het vir jouself 'n karakter of 'n label gegee en ek het 'gefight' om dit te hou.

Wat as my vriendin kom kuier om my te bemoedig op die einde was dit ek wat haar bemoedig, maar ek was die een wat deur iets gegaan het.

It seems that Pamela's positive view of herself became a self-fulfilling prophecy and instead of being the one supported or 'ministered' to, she found herself supporting and 'ministering' to others and helping them to cope with her illness.

Although Dick accepted that his illness demanded certain changes in his lifestyle, such as slowing down, he was still defiant in being who he has always been – a driven successful, type A personality. Dick was defiant in keeping his identity. He said:

I have no intention of retiring, becoming an old vegetable, who just sits there. I keep on striving to grow more and more.

You know, I joked and said I'd like to get out of the business that I am doing. Well, it doesn't matter I would not do anything else- I sort of said I like to have a boerewors roll stand on South Beach, but if I do I will like to have a salad bar next door and an ice cream bar on the other side...I do not know how not to drive.

Accepting that he had to slow down, as a result of the changing circumstances the illness had brought, but at the same time expressing the need to still achieve, may be a strategy to maintain some form of continuity; to balance change with sameness.

Gloria, like Pamela and Dick is defiant in keeping her identity as a 'coper' who deals with whatever is thrown at her. Referring to her illness she responded as follows:

Ja, ja because as far as I am concerned these things happen and one gets on with it, it is not something that I feel negative about. It does not impact on my life.

And fuck just leave it, it has nothing to do with anything. I get on with life.

I love life and I am busy and I enjoy every moment of this – I can be dead this afternoon or tomorrow. So, and I have always been like that. So you know, whatever gets thrown at me I deal with it, I am not going to sit down and feel sorry and sulk...

Even though this illness impacts on her life, she compartmentalises it in a way that denies its impact, choosing instead to carry on with her life as she always had before.

Defiance in Maintaining a Way of Life

Gloria was also defiant in maintaining her way of life and making her own choices in spite of the rigid treatment regime Diabetes demands from its sufferers. She said:

... if I want the milkshake I will have it.

If I want that chocolate I am going to eat the chocolate and I am going to enjoy every little chew- and that will be that...

In her defiance to maintain her lifestyle, she needed to make her own choices, which is possibly also a strategy to stay in control of the illness.

Acceptance vs. Rejection

Being diagnosed with a chronic illness and living with the illness demands that its sufferer goes along with the process that will lead to acceptance of the illness and all the possible implications for one's life. It is not only the illness that needs to be accepted, but also the treatment offered by the medical professions. People, diagnosed with illness also find themselves in the position where those who are not professionals also offer them advice on how to live their life with an illness. In the stories of the participants, acceptance on various levels emerged, but also rejection of some of the recommendations from professionals and lay people alike. They wanted a choice in what they accept and what they reject. It seems that the only way to accept an illness as part of one's life is through being able to reject some aspects of the illness or the help or advice that has been offered.

Acceptance of the Illness

Acceptance of the illness was a theme that emerged from the stories of the participants. It seems that patients had to come to terms with the reality of the illness at some point.

In adjusting to changing his lifestyle to cope well with the illness, Dick had to come to terms with it. He said:

Because I have to come to terms with the fact that there is no cure. I have identified that it is there, I identified how I feel and I identified what I need to do.

It has to be done. You know, as exactly as I have said now, thirty odd years ago when I became a manager for the first time, I had to do, make certain changes to be able to do that. I now have to make

other changes to be able to do this. ...I am sitting down and saying what I need to do and I am looking at it step by step by step to be able to, to live with this and to be able to change.

It seems that in accepting the illness and the changes it demands Dick, used the same strategies that worked for him as a businessman.

Diabetics have to follow a strict regime of testing blood sugars, administering insulin injections as well as having to adhere to a diet programme. Gloria accepted this and integrated it into her lifestyle.

I have to. Absolutely have to, it is part of my life and if I don't take note of it, I can't ride my horse, I can't go to gym, I can't...

...you know it becomes, just becomes like brushing your teeth. You know you get up in the morning and you brush your teeth. So it just becomes a routine, part of your daily routine.

She also accepted and integrated the illness as part of her life.

So, I don't see this as a unfortunate thing, I don't see this it negatively, I see it sort of as a slight irritation, but if I am going to have a disease this is the one I rather have above all the other diseases, this one is fine, I am happy with this one.

Accepting her illness seemed to give Gloria a sense of control and allowed her to continue her active lifestyle. The illness became 'part of' rather than ruling her life.

For Pamela, on the other hand, the diagnosis of Breast Cancer was so overwhelming and traumatic, that she reacted in shock and disbelief. Everything seemed to happen so quickly, that she still today experiences some feelings of dissociation of being diagnosed with Cancer. For her, acceptance was on the level of accepting the words of her doctor without ever questioning them. She experienced the whole process from discovering the lump to the doctor's fateful verdict as rushed and she felt out of control. In a sense all the control was in the hands of the doctors and she just accepted whatever she was told.

Today, she regrets not asking more questions concerning her fate. In reflecting back on that moment of blind acceptance, she describes it as the most traumatic moment of her life. She said:

Ek is in myself spyt dat ek dit so dadelik aanvaar het- die ergste. Ek het agterna gedink kon ek nie net eers voor ek dit gevat het as 'final' net eers 'n bietjie daaroor gedink het nie of bietjie oplees, maar ek was onmiddelik negatief ek was onmiddelik asof iemand klaar dood oor my gespreek het. Ek het klaar begin oppak.

So alles het toe so vinnig gebeur ek moes... dit was ongelooflik ek het daar gesit en huil, vreeslik, jy weet, want die skok...

Perhaps at that moment the professional's diagnosis so crushed Pamela that she could not even contemplate a choice; maybe she was not even sure that she had a choice. So she just accepted it.

Rejection of Advice

Rejection of advice is another subtheme that emerged as the sufferer was exposed to all kinds of advice from people who think they know something about the illness. People usually give advice as they believe they are being helpful. However, sufferers often do not find it helpful, but rather experience it as intrusive. Dick said:

I also find every second person who, who is a sufferer of the same thing will tell you that they have found some wonderful doctor who did this and somebody else some wonderful diet that did... someone else something wonderful that... I am not sure that, you know, that any of this really helps, because I don't know of anybody that genuinely had the same thing that has been totally cured.

Chronic illness demands that sufferers seek advice and treatment from the experts, the professionals in the medical field. However, advice from the 'experts' also differed and led to the rejection of advice given by the experts in some cases. Dick said:

Somebody else that I know suggested to me that I, I needed to go to a certain dietitian, who concentrates on this kind of thing and I've tried it, cost me an absolute fortune for funny muti and it did 'buggerrol'. Somebody else suggested that there is a doctor who draws bloods and sends it overseas and... I am not going to do that either.

Gloria found the advice given by the professionals as conflicting and not individualised to her specific needs. She said:

...the GP's are completely useless, they are completely useless...

I then saw a physician that came to see me in hospital, he, he, when I look back on it now, he knew nothing, nothing about Diabetes, giving me bad advice, he was, you know, they don't know how to control it, they don't know anything.

The dietitian also was just floundering, trying to make me eat this and that and the next thing- that was all just absolutely wrong.

The lack of consensus among professionals seems to add to the anxiety experienced by sufferers making them less confident in the professionals and more likely to reject their opinion.

Rejection of the Illness Itself

In Pamela's case the rejection was of the illness itself. She said the following:

Ek het so 'n haat aan kanker nou. As ek hoor van mense wat kanker het wil ek daar wees om te ondersteun, want ek weet kanker is nie van die Here nie. Kanker is van die duiwel en ek is woedend...

...want ek het vir myself besluit, ek sal gesond wees, ek sal dit nie aanvaar nie.

It seems that to cope with something as life-threatening as Cancer, it is necessary for the sufferer to treat it as an 'enemy' and to reject it. This seems to be the strategy that Pamela used to cope with her Cancer. This is in contrast to the other illnesses, such as Diabetes

and Chronic Fatigue Syndrome which requires an acceptance and integration for the sufferer to gain control over the illness. The Cancer sufferer cannot allow or invite the Cancer in; to destroy it, he or she has to reject it.

Connection vs. Disconnection

When diagnosed and living with a chronic illness the sufferer seems to have a greater need to connect with other people – family, other sufferers and the professionals. It may also be a time when one's connection to God or a Higher Force is re-evaluated and new, more meaningful connections may be established. It is within these connections and relationships that the sufferer may develop new identities and gain mastery and a sense of control over the illness. However, the journey of living with a chronic illness is also marked with periods of feelings of disconnection with family members, friends and the professionals. Feelings of being even disconnected from the illness itself may also emerge.

Connection with Loved Ones

When her doctor told Pamela that she has a life-threatening Cancer, the first thing that she did was to phone her mother. She said:

En ek onthou dat ek my ma gebel het toe ek uit in die kar geklim het, onmiddelik.

Jou ma is vir jou 'n standvastige figuur, iemand wat vir jou deurdra wanneer dinge verkeerd gaan, as iets verkeerd loop weet jy jy kan jou ma vertrou, sy gaan vir jou dalk sê wat moet jy doen of vir jou raad gee of wat ook al.

It seems that the connection with her mother made her feel safe.

She also felt connected and supported by other family members. She said:

Ek is nie alleen nie. Ek het my skoonma gebel en ek het vreeslik gehuil en sy het gesê 'O, ek wens ek kon nou daar gewees het om jou 'n drukkie te gee, maar ons bid vir jou.' En toe het die familie een agterna die ander een gebel.

And it seems a network of potential support was mobilised.

When Dick was experiencing the debilitating effects of his illness he needed his wife's support, as well as his staff members' support. He said the following:

...she (his wife) is extremely understanding, extremely supportive and I am in a similar situation with my general manager at the office. It was an eye opener to me when he said I knew there was something and I will always be there...

It is almost as if the breaking of the news to people invites or elicits their support.

Connection with Other Sufferers and the Professionals

Pamela found that the connections and the relationships with the medical staff and other Cancer sufferers made the process of her radiation therapy bearable as well as meaningful. In connecting it seems that the responsibility of suffering is shared. Pamela said:

Maar toe ek nou deur die bestraling gaan en jy begin die susters om jou leer ken, was dit vir my makliker om mee te 'cope'...

These connections with professionals seem to strengthen her, giving her the courage to cope.

Connection with other sufferers seems to create a community of sufferers that gives everyone a sense of not being alone in their fight against their illness. She said the following:

Ja, en ek het na mense gaan luister wat gepraat het oor borskanker, sulk ‘talks’...en dit het vir my baie beteken, want ek was daar tussen ‘n hele klomp vrouens wat almal in ‘n seminar gesit het, wat almal borskanker gehad het. Ons was nie verskillend van mekaar nie...

Pamela also found that in her connection with other sufferers she could reach out to them, which gave her life and illness, at that point in time, meaning. In comparison to other sufferers, she seemed better off, which made her feel stronger and more able to cope. She said.

Toe ek deur die storie gaan was daar ‘n jong meisie wat net getroud was wat deur Breinkanker gegaan het, sy het deur bestraling en chemoterapie gegaan. So ek het sekere mense geleer ken saam met wie ek die pad moes stap, jy weet.

The diagnosis of Chronic Fatigue Syndrome has been questioned by some medical experts who deny the existence of it as a ‘real’ illness. For Dick, the connection with his doctor and psychologist, and their acknowledgement of what he was experiencing, was a source of support. He was taken seriously and his suffering was acknowledged and thus gave him a sense of support. Dick said:

...you know I see my psychologist and my doctor, Dr.C and I have been fortunate that he has no question at all in his mind that this exists.

Although Dick would like to connect with other sufferers, he has been unsuccessful as very few support groups exist and he is experiencing a sense of isolation. He said:

One of the things that I said in that article, you know, if I were an alcoholic or a drug addict there are dozens of support groups around, but I don’t know of any?

Silence seems to accompany this illness, making connection with other sufferers less likely. A likely source of support is thus denied these sufferers.

For Gloria, the mastery and control of her illness became a reality when she found a doctor, with whom she connected. He listened to her and gave her advice that made sense to her. This highlights the importance of fit in terms of what others suggest to a sufferer. This connection is ongoing and today, ten, twelve years later they still have a meaningful doctor-patient relationship. She commented:

And he knows what he is talking about, he tailors it to the individual, he listens to the person, you know...

Yes, I trust him completely and utterly. And you know, he I will tell him what I have eaten, what I have done, I have tried this, tried that, that was not so good, that worked very well and he, because I am very controlled I think he is quite happy to experiment with me...

I trust him enormously. If he had to leave the country I would be very sad about it.

It seems that Gloria and her doctor formed a co-operative relationship in managing her Diabetes. This relationship seems to be built on trust, as Gloria follows his advice and he also gives her control through letting her make her own choices, thus trusting her as well.

It seems that the participants created a network of support through connection with either other sufferers or the professionals treating their illness. It seems that the connection with the professional is significant in the control of the illness. The advice given, as well as the acknowledgement of the suffering or experience of the patient, seem to be important factors in establishing a meaningful relationship.

Connection with God - a Spiritual Anchor

For Pamela the experience of illness reconnected her with God. When her world was no longer predictable, she turned to God. She said:

Ek dink so, ek dink vir my wat ek daardeur geleer het, vir my was dit heeltemal geestelik, OK vir my het ek vasgegryp aan die Here meer as enigiets anders... So, as ek nou terugkyk was dit vir my waar my Christenskap vir my waarde begin kry het, waar ek regtig kon sê die Here het my deurgedra.

The other two participants did not refer to this.

Although the participants' journey of living with a chronic illness brought new connections and highlighted old connections, there were nonetheless periods of disconnection and isolation.

Disconnection: Dealing with the Illness Alone

Pamela also experienced a need to be alone. She seemed to realise that the responsibility to cope with her illness was hers. Paradoxically, in spite of all the support, she experienced times of isolation and disconnection. Pamela said:

...ek wil net op my eis wees, ek wil 'deal' met hiedie ding, basically.

En daar is net niks wat niemand of iets wat kan help om te sê, 'hoor hierso dit gaan regtig OK wees nie'. En in daai paar dae moes ek 'cope' met toe ek nou alleen is met myself...

Gloria, realised early in her illness, that ultimately she has to take all the responsibility for her illness and to deal with it herself. This tended to make her feel disconnected from others and very alone. She said:

...nobody else can take charge of this, I have to. Dr.D can help me and Dr.D can advise me and Dr.D can tell me the latest things that are happening, but at the end of the day I go home and I have to deal with it.

This way of coping seemed to be her pattern as she was always a private person. Thus being alone and the distance it might have given her, allowed her to cope.

Disconnection with the Professionals, other Sufferers and Friends.

Pamela experienced disconnection in her relationship with the doctors who were treating her. She said:

...maar hulle kom eintlik koud voor, die medici. Hulle is koud teenoor jou saak, hulle is nie ongeskik of so nie, hulle is vriendelik en behulpsaam en alles, maar hulle is nog steeds koud teenoor jou.

...en ek het nooit weer teruggegaan nie. Nooit weer nie, daai attitude...ja, en toe loop hy (the doctor) nog voor my en hy het nie die deur vir my oopgemaak. Hy het amper die deur in my gesig toegeslaan. Net daai attitude...

It seems that she felt the boundaries that the doctors erected kept her disconnected from the support she expected from them.

Dick experienced some disconnection and isolation from people who do not understand his illness and do not always respond in a supportive manner. This seems to have silenced him. He commented:

Ja, from people who don't know, you mention to them and it is shock horror, how terrible for you, because I believe its really debilitating then they get bored very quickly, so you get very, very little support from people who are not sufferers...

And what I've learned is that as far as they want to know, they don't wanna know...

It seems that sufferers of chronic illness have different needs and not everyone desires connections with other sufferers, like in the case of Gloria.

She said the following:

I don't need to know that, definitely I don't need to know other people's horror stories; you know I am just not interested. I

definitely don't go to support groups or speak to diabetics about their nasty problems, no.

Gloria's desire not to share her illness with other people, seemed to have silenced her in the same way as Dick, who expresses the need to share, but is silenced by the reactions of others. Both of them seemed to experience disconnection and isolation with regards to others.

Disconnection from the Illness

Pamela at times even experienced disconnection from the illness or the experience of illness. She said:

...ek praat dan dink ek aan my lewe soos dit was sonder (Cancer)...vir my partykeer is dit so moeilik om regtig te realiseer waardeur ek gegaan het. Want dis asof ek nie daardeur gegaan het nie. Sjoe, maar ek is daardeur, jy weet. En ja dit is amper asof jy nie daardeur gegaan het nie. Dit is asof dit met iemand anders gebeur het, maar jy weet jy het daardeur gegaan, want ek meen jy het die merk op jou liggaam en goed om te bewys jy is daardeur.

Maar ek meen, jy voel nie siek nie, jy voel niks nie, dis net die dokter het 'n doodspraak oor jou lewe gegee, jy weet.

Pamela's feeling of being disconnected from the illness may be related to the severity of an illness such as Cancer. Again, to cope and to recover she could not allow the Cancer into her life. She had to disconnect from it. Her disconnection may also be related to the rushed process from diagnosis to the treatments of surgery and radiation therapy. It all seemed to happen so fast that she experienced it as not being 'real'.

From the stories of the participants it may be concluded that the experience of chronic illness presents with a paradox of connection and disconnection. It seems that participants on the one hand need the connection with the professionals, loved ones and possibly other sufferers to create a network of support, which helps them to cope. On the other

hand, they also need to deal with the illness on their own; they need to take responsibility for coping with the illness and this seems to be a lonely and isolated, but necessary process. They also seem to find themselves in a network of support, but nonetheless still may experience disconnection and isolation. They may also choose disconnection as in the case of Gloria, who did not desire contact with other sufferers. This may be interpreted as a strategy to distance oneself from your suffering in an attempt to cope.

Loss vs. Gain

Being diagnosed with a chronic illness implies loss of one's health and physical abilities. These abilities, one used to take for granted, may become more difficult to carry out, as chronic illness is degenerative in nature. Even if the sufferer is not experiencing loss of any physical abilities at the time of the diagnosis, the nature of chronic illness implies possible loss in the future. All three participants experienced physical loss or are contemplating loss in the future. They did not only experience loss of physical ability, but experienced a sense of loss in various areas of their lives. In contrast to the loss experienced as a result of illness, participants also experienced gains. The participants' stories became stories of courage and gains. Through the process of dealing with their illness they gained mastery and control as well as new identities and insights.

Loss of Physical Ability

Loss of physical ability manifests in different ways.

For Pamela the possibility of losing a breast was very real, although she did not have a mastectomy. She described her anxiety of waking up after surgery and not knowing if she still had her breasts as follows:

Dit was vir my ook traumaties, want jy weet nie as jy uitkom, wat gaan vir jou lê en wag nie. Het jy 'n bors of het jy nie 'n bors nie... ek weet nie wat, dit voel weer dis jou vrouwees wat aangetas is, jy weet.

In spite of responding well to treatment, sufferers are always aware of the possibility of physical loss. Pamela is still living everyday with this possibility which is an ongoing struggle in her mind. She said:

Die eerste ruk, ek moet sê die eerste jaar het ek baie gesukkel, want dis altyd in jou agterkop, dis altyd. As ek werk toe ry en ek kry ewe skielik 'n pyn, ek moet sê vandag, partykeer kry ek 'n pyn en dis dadelik in my gedagtes. En dis altyd 'n stryd en dis altyd iets teenoor wat jy moet baklei, regtig, jy weet, want die simptome kom terug, 'basically'.

The most debilitating symptom of Dick's illness is the fatigue. He said:

I thought I was going to fall over –I was just so exhausted, absolutely.

This morning I said to her (his wife), we were having lunch; I said to her, I must get home, I was so tired, I must go and sleep.

Diabetes is a degenerative illness and the risks of possible complications as a result of living with it for years are real for its sufferers. Gloria is aware of the possible loss of physical abilities which may arise from her illness over time. She commented:

...but the thing is I have got to, you know the one thing I do have to understand as I said earlier, my life will be shortened because of Diabetes and I do have to understand that possibility as one gets older the diabetic influence on the body might cause a problem.

I have to try harder. Because it is my health. I don't want to lose my vision or my toes or my legs or my kidneys or whatever.

Although Pamela did not have a mastectomy, she always is aware that maybe in the future it may be necessary. Her response to this seems to be that of a fighter, she does not allow mentally for the Cancer to come back.

It seems that for Dick living with chronic fatigue impacted on his relationship with his wife as he is not always able to participate in activities they used to share. This loss of physical ability may also present a loss of social roles as the disability forces the sufferer to at times withdraw from social interactions or activities. The possibility of loss of physical ability puts sufferers in a perpetual movement 'in' and 'out' of fear.

Gloria, on the hand treats the possibility of physical loss in the future by trying to rigidly control her illness and she pushes herself constantly for perfect control.

Loss of control

When a chronic illness is diagnosed or when the affected person is experiencing symptoms, feelings of loss of control may emerge.

Pamela describes the feeling of losing control graphically, when she was diagnosed with Breast Cancer as follows:

...op daai oomblik het ek probeer vasgryp aan lewe en dit het gevoel of ek sand gryp en ek kry dit nie in my hand vasgehou nie...

En daar is geen beheer, en daar is geen 'way' wat jy kan probeer beskerm of daar is geen manier hoe jy jousef kan help op hierdie stadium nie, jy is afhanklik van ander mense om te weet wat hulle doen.

...want jy wil vasgryp aan iets of iemand, maar daar is niks wat jy kan aan vasgryp nie...

Dick, who comes across as a very driven, successful man felt he could not cope with life when he started to experience the symptoms of his illness. This seemed to be a new experience for him which he found very distressing. He said the following:

It started when I realised, it started with a very much stress related thing, where I felt that I was not coping-I just was not coping with life.

On an emotional level I was battling to cope and eventually I reached the stage where I constantly were getting down and depressed and constantly... I just wanted to run away...

Gloria on the other hand made a conscious decision not to allow herself not to be in control of her illness and denies any feelings of losing control. She said:

Well, I think if I have to have any illness I would prefer to have this one - at least I can control it. It does not control me where I think lots of other people's illnesses control them.

Well I would not wish it (Diabetes) on anybody, But I rather would have this one, because it is possible to control it, it is not something you lie down and go 'Oh God, I am diabetic that is the end of my life' ...

Loss of Dignity

The radiation therapy made Pamela feel exposed and vulnerable. She experienced a sense of loss of dignity, when she had to undress in front of strangers and had to have her body marked for radiation. She also experienced loss of dignity as she had to walk around with a catheter, days after her surgery. She said:

Veral jy weet, jy moet jouself 'expose', hier moet ek by die dokter gaan lê. En jy moet uittrek voor hom, en ek is 'n baie private mens, jy weet. Dan teken hy op jou liggaam, nou daar moet die bestraling en dan moet jy na 'n ander kamer toe gaan, daar moet jy weer gaan lê, 'n ander klomp vrouens.

Ek onthou nou net dink nou net aan daai 'drainage' wat hulle vir jou insit, waarmee jy moet loop...dit was ook so 'embarishing' ...

Loss of Identity

A theme of loss of identity emerged. A chronic illness seems to threaten the sufferer's identity. The physical effects and the possible implications of the illness may challenge his or her identity, as well as the roles he or she fulfills. Our perceptions of who we are may be defined by our roles and the way we see ourselves as well as how other people see us. This identity may be shattered if the illness forces a person to integrate different and opposing perceptions of him - or herself from those he or she is familiar with.

It was very difficult for Pamela to acknowledge the feelings of depression that the illness brought, as depression did not fit with the way she or others perceived her. She commented as follows:

Dis hoe ek voel. En ek is nie eintlik 'n depressiewe... maar ek dink dit was net so 'n groot iets om te 'deal'...

Ja, in 'n sekere mate was ek bang om dit toe te laat (the depression), ek weet nie waar dit my sou neem nie.

Jy leer gou-gou, wat ek gewonder het, is wie is ek, want ek het probeer 'cope' met verskillende... nou wil ek in depressie ingaan, maar dis nie wie ek regtig is...

It seems as if Pamela fought to keep her identity as she did not allow the depression to become part of her identity. It seems that she fought the 'monster' of depression in the same way she fought the Cancer. To cope, Pamela could not allow either one into her life.

The struggle with possible loss of identity is expressed by Dick as follows:

I do not know how not to be me.

You know I am a guy that always been very active, I used to ran Comrades when I was younger, I always been my entire early adulthood I was very fit, very active and this is a very different feeling for me, very different.

In contrast to Pamela it seems as if Dick did integrate his new identity as his view of himself had changed. He no longer sees himself as the active, sporty guy he once was, but had to rebuild his identity by excluding certain familiar qualities.

Gloria, on the other hand did not experience a sense of loss of identity as she felt the illness did not impact on her or the way she perceived herself. She is more concerned that other people may perceive her differently if they know she is diabetic. She therefore kept her diabetes shrouded in silence.

...I say I am a very hyper person, I get things done and I got a 21st coming up on Friday, Saturday and you know... I am always like that, I have been always been like that – I can't sit still... I am not hyperactive, because I am diabetic; maybe I am diabetic because I am hyperactive...

...so I don't tell a soul...

Nobody, OK, my dentist knows, no my dentist does not know, no my dentist does not know, my doctor knows that I am diabetic, nobody else knows- why does my dentist needs to know...because it is such a nothing event, is it not? It is not making changes to anything it is not doing anything, it is just sort of there...

The participants seem to respond differently to the threat of loss of identity. Pamela reacted as a fighter for and protector of her identity, whereas Dick was in the process of accepting and integrating new identities. Gloria reacted in silence as a way of maintaining control, of her illness, and also her identity.

A theme of gain emerged from the stories of the participants. All three participants developed strategies to gain control or mastery over the illness.

Different strategies were implemented, but all three participants compared their situation to those less fortunate than themselves and used this as a strategy to gain mastery and control over the illness.

Gaining Control and Mastery through Comparison to Others

In being in the company of other sufferers, Pamela compared herself to others and realised there were those worse off than her. She said:

Want ander mense se probleme lyk altyd vir jou erger, as waardeur jy gaan en as jy na jouself kyk dan dink jy, maar sjoe ek is gebless. Dit waardeur ek gaan is nie so erg nie. Toe ek deur die storie gaan was daar 'n jong meisie wat net getroud was wat deur Breinkanker gegaan het, sy het deur bestraling en chemoterapie gegaan.

This made her focus on her 'blessings' and see her suffering in a new light.

Even though Dick is not in a support group he nonetheless knows others who have a similar illness to his and he feels that he is handling the demands of his illness better than other sufferers. He said:

I know a woman in Durban whose got a similar kind of thing and she is allowing this thing to beat her, because she refuses to pace herself, she sees it as if she does not work a full week...it is a weakness. And you know her approach is that as a result she is in a very much worse way than I am, I mean if I get a very bad time and I get to lunch time I am tired I will just quit.

Here Dick also acknowledges that he paces himself, goes with the process and takes a rest whenever his body tells him to. It seems that through accepting his illness and integrating new identities he is gaining control and mastery in living with the illness.

For Gloria, her illness was just much more bearable than any other illness she could think of. She said:

Well, I think if I have any illness I would prefer to have this one- at least I can control it. It does not control me where I think lot's of other people's illnesses control them.

She also felt that the fact that she had Type I Diabetes puts her in a more fortunate situation than those diagnosed with Type II Diabetes. She seemed to have more control over it as Type I Diabetes is treated with exact measurements of insulin, whereas Type II is treated with oral medication, which cannot be measured exactly to the individual's needs. The fact that insulin can be measured so accurately seems to strengthen her belief of absolute control over the illness. Being able to do something so accurately seems to fit with her as a person who likes to feel in control. She said:

You see the insulin is so easy to deal with. OK. It involves injections and pricking your finger it is some sort of pain, but it is so much precise, those tablets are ridiculous, you know everybody I know that is a Type II diabetic, they all die young, they all end up with major kidney problems and so on, because those tablets are really not good enough.

Comparing oneself to others whom you perceive as worse off than yourself seems to be a strategy which all three participants employed to gain control and mastery.

Gaining Control and Mastery through their 'expert' status

Gloria believed that she is unique and not like anybody else. She is the 'expert' on her illness and used this belief to gain control and mastery. She said:

...I don't believe that people, unless they very, very clued up, unless they are diabetics, I don't think they can actually hand out advice, because it is such an individual thing...

You see because I know my body better than the man across the desk.

It seems that this belief challenged professionals with whom Gloria was in contact in the earlier years of her illness. She expected to be treated as an individual and rejected advice that she perceived as not suitable for her. Managing her own illness on her terms seems to be a significant factor in her feelings of control and mastery. However, Pamela and Dick did not share these feelings as Pamela was so overwhelmed with her diagnosis that she never questioned the 'expert' status of her doctors. Dick on the other hand did not question his doctor's opinion, but he did not regard all advice given to him as useful. For example, he did not find the advice from the 'expert' dietitian in Chronic Fatigue Syndrome helpful. Although they were less assertive in claiming their own 'expertise' regarding their illnesses than Gloria, they nonetheless managed their illnesses.

Gaining Mastery and Control through Knowledge

Pamela sought knowledge about Breast Cancer through joining support groups and reading about cancer and healing. She said:

Ja, en ek het na mense gaan luister wat gepraat het oor Borskanker, sulke talks.

Ja, ek het baie boekies en my ma het vir my boekies gegee, ek het baie gelees, goed wat my nie toelaat om 'down the dumps' te gaan nie.

This seemed to empower her and lift her spirits.

Dick searched for knowledge with which he could identify, in an attempt to gain control and mastery over his illness. He said:

That was now 18 months ago and reading everything that I could read about Epstein- Barr didn't tell me or didn't tie in to what I was feeling, it was very different. Until a friend of mine in the medical aid business send me something that had been written and I do not know who wrote it by a American in which he had Epstein-Barr and than a second

thing called Chronic Epstein-Barr and it was only when I have read that that I said...that it was written for me

In Dick's search for answers, he did not give up until he found something he could relate to. He also used this information in an article he wrote to express his experiences in living with his illness. In writing this article he was able to reflect on the process of what he was going through. He also gave his article to his wife to read, which may have broken his silence and given him control and mastery.

Gloria also sought knowledge through reading and searched for an expert whose advice she felt she could trust. She said:

I knew nothing about Diabetes; I started reading up about it. I then was going from one person to the next, speaking to people.

Gloria, like Dick kept on searching until she found the knowledge that made sense to her. It was only when she found the doctor, whose advice she accepted that she really gained control over her illness.

Gaining Control and Mastery through Knowing Why

In the process of gaining control and mastery participants seem to need to know why they became ill. In knowing why, they felt less vulnerable and felt more in control, because they were then able to make the changes that would protect them against the illness.

In Pamela's case she believed that her illness originated from issues in the past that she had not dealt with properly. In seeking therapy to resolve these issues she felt she was able to protect herself against the Cancer from spreading or reoccurring. She said:

Ja, waar kom dit vandaan? Ek meen as dit nie in jou bloedlyn is nie dan word jy 'basically' gestraf vir iets jy weet. Is dit miskien die prys wat jy betaal?

Toe ek beseft ek ek het regtig bitterheid in my lewe en onvergewensgesindheid en dit was vir my 'amazing'. Ek het gedog, joo hoe is dit, ek meen jy weet jy voel dis onregverdig, jy weet, jy dis nie asof jy dit bedoel om bitterheid te gekoester het nie, maar jy het tog 'subconsciously' het jy dit gedoen, jy weet en dis die prys wat jy betaal daarvoor.

It seems that working through these 'issues' left Pamela feeling protected from the Cancer. Cancer came 'out of the blue' and therefore it was important for her to identify some cause she could act on, in an effort to prevent reoccurrence. This also seems to fit with her image as a 'fighter' against the Cancer. She however, in retrospect acknowledged that the Cancer was not necessarily a punishment, but rather a culmination of factors.

Dick believed that his driven type A personality and his hectic lifestyle brought on his illness. He seems to feel no guilt or regret as he believes that it is the way he is. He said:

And I guess I am when I hear what type A personality is- I have no great regrets that I am a type A personality, because I think to be anything other than that, must be awfully awfully, awfully boring, so I have no regrets, there are downsides, the downside of what I am going through.

I also have no doubt at all that it is because of the way I am and I have been working and stresses and that sort of thing that flared this thing up and caused it to be reactive, I have no doubt at all about that.

It seems that Dick gain control and mastery through the process of accepting that maybe his lifestyle and personality had caused his illness. However, he has no desire to change, but is integrating his personality with the demands of the illness. He seems to be proud of who he is, but is well aware of the consequences of his choices. Control may emerge from the acceptance of the illness as well as in choosing how to live with it.

The etiology of Diabetes is still a mystery, although various theories of etiology exist, the medical fraternity is not clear on why people develop Type I Diabetes. From Gloria's

story it seems that the cause of her Diabetes is the missing piece of the puzzle. When she finds this answer she believes she will gain control and mastery of her illness completely. She said:

One wonders why, what did I do wrong. Did I do something, was it something I've picked up or was it just my genetic make up.

Gaining Meaning

In spite of their losses, all three participants were able to reach a point where they believed that the illness brought meaning to their life. It seems they were able to reflect on the experience of having the illness and how their life eventually benefited from the illness.

Pamela gained meaning through creating a new identity. She maintained her identity as 'enthusiastic' not allowing depression to form part of it, but instead created a new identity. As a Cancer sufferer she felt vulnerable and became a 'victim' of the illness. She then became a 'survivor' and reached out to other Cancer sufferers, which gave meaning to her life. She was not a victim of the illness anymore and became a 'rescuer' in helping others. She said:

So 'n mens kry 'n passie, hulle sê mos as jy deur iets gegaan het, wil jy uitreik na iemand wat deur dieselfde gaan, omdat jy weet waardeur hulle gaan. En dis hoe ek voel daaroor. Soos 'n meisie wat saam met my gewerk het, toe die eerste ding toe sy dit kry toe bel sy my. En jy voel jy kan daar wees vir mense en iets beteken in hulle lewe, jy weet. Gee 'n biejie sin in die lewe ook vir jou.

Sodat een van die dokters, sielkundiges in die onkologie sentrum vir my gevra het of ek nie wil insit as 'n om vrouens wat deur daai goeters is te help. En ek was great...

The new identities of a 'survivor' and a 'rescuer' made Pamela's journey with Cancer meaningful. It also empowered her, which seems to give her a sense of control and purpose.

Dick in reflecting on his illness was able to see it as a new beginning, in the sense that it forced him to slow down and possibly enjoy life more. He is also contemplating the possibility of the illness saving his life, as if he continued his previous lifestyle, he might have developed a heart attack as a result. He said:

It is negative from the point of view of what it has done to me physically, no question at all about that, but from the point of view from in which...you know I am 58, so when people get to 58 they supposed to have made it to a very large degree, your kids have grown up, you don't owe anything anymore very much and that is the way we are in terms of a state of living. I don't know maybe one can be totally philosophical about it and say well; maybe this came along to say to me this is reward time now.

I think with nature - you don't mess with her and when people work to that degree something happens; I guess I am lucky, I guess I am lucky this is what happened to me where other people just have a heart attack and cheers...

It seems that the illness forced Dick to reflect on his life. He was able to find meaning in all the possibilities the illness brought, such as more time with his family, enjoying all the years of hard work and to take better care of himself.

For Gloria, in acknowledging the possibility of a shortened lifespan due to illness, living with the illness highlighted life for her. She always felt she was someone that has lived life to its fullest, but on some level the Diabetes highlighted her positive attitude to life. She said:

I think, possibly as I say I have never been someone who is worried about the future. I live in the present, very much, I have never live in the past, either, I don't take have a camera, for example. I don't take pictures, because I do not believe in

looking at what happened then, it is all here, so I am a very present focused person, but ja, possibly this (Diabetes) make it more so.

Gloria seems to live each moment to the full, heightened by the knowledge that life can be curtailed at any moment.

In the next section the personal reflections of the researcher will be discussed, as this influenced the way in which the themes were identified.

Personal Reflections

The Voice of the Researcher

In my conversations with the sufferers of chronic illness I was struck by the strength and resilience of people. I came across defiance in the participants to maintain their identity against all odds. If the illness in anyway challenged their identity they re-invented themselves, and in spite of the physical implications of illness, refused to give up the 'sense of who they are'. All three participants came across as strong-minded people who will cope with whatever comes their way. In the conversations I had to 'push' to see their vulnerabilities as they seemed to managed their illnesses so well.

With Pamela I found that regardless of how bravely she handled her illness and how she was admired by outsiders for her strength and faith, the illness is still something she lives with everyday. How deeply it affected her and how close she was to a deep depression is something she still continues to hide today from her loved ones. I found this conversation touching and it made me feel vulnerable. Pamela and I are of the same age and are both mothers. If Cancer can happen to her, it may happen to me as well.

Dick seems to have integrated his illness on an intellectual level, but still struggles to slow down and practically to implement not to be a workaholic. To not be as driven on

some level still seems to be a weakness for him. He wants to slow down, but still describes weeks that will be exhausting for most people.

Gloria was afraid that, in spite of all her efforts she still may end up with some complication from the Diabetes. The conversation with Gloria was difficult in the sense that she does not allow her illness to significantly impact on her life, which as a result made it more difficult to relate to her experiences.

The question I sit with is: Is this how most people respond to a chronic illness or did I attract these participants who like to be in control and may be described as ‘copers’? As I talked to them I could identify with them on so many levels. I myself have been labeled as a ‘coper’ and someone who always wants to be in control. I do not like to be a victim or not to be in control myself. It is a much safer place to be the ‘rescuer’ than to be a victim, so I could fully understand why Pamela in her deepest crisis reached out to others.

The most difficult part of the conversations for me was the boundaries of my role. My role, as the researcher was to engage with the participants in a conversation about their experience of living with a chronic illness. I reflected on what they were saying and also in my reflections brought possible new meanings. So in a sense my role was therapeutic, but not on the level of being the therapist. In my conversation with Pamela this was difficult as part of me wanted to be the therapist and a part of me was cautious as my role was that of the researcher. This was especially difficult in relation to Pamela’s feelings about not going for her regular check-ups, as she sees this as not having faith in her complete healing. As a therapist with the possibility of follow-up sessions I probably would have challenged her more and, as I also see myself as a ‘rescuer’ I would have tried to encourage her to go for her check-ups. In my role as the researcher, I was careful not to push too hard, as I felt my role as the researcher was not to breakdown defences and leave the participants disempowered. However, I still experience some guilt in not taking the position of the ‘rescuer’ in trying to convince her of the necessity of going for her check-ups.

Conclusion

The themes identified from the stories of the patients living with a chronic illness may be summarised as follow:

- Fear vs. Defiance

Sub themes that were subsumed under the abovementioned theme included the following: fear of the unknown, fear for those we love, fear of being labeled and judged, fear of physical disability, defiance in keeping identity, and defiance in maintaining way of life.

- Acceptance vs. Rejection

Sub themes that emerged from the abovementioned theme included the following: acceptance of the illness, rejection of advice and rejection of the illness itself.

- Connection vs. Disconnection

Sub themes included in the abovementioned theme included the following: connection with loved ones, connection with other sufferers and professionals, connection with God, disconnection; dealing with the illness alone, disconnection with other sufferers, professionals and friends and disconnection from the illness.

- Loss vs. Gain

Sub themes that emerged included the following: loss of physical ability, loss of control, loss of dignity, loss of identity, gaining control and mastery through comparison to others, gaining control and mastery through knowing ‘why’ and gaining meaning.

Central to the experience of being diagnosed with a chronic illness seems to be fear. Although this fear is acknowledged it is met with defiance as participants did not allow the fear to paralyse them in managing and coping with their illnesses. In coping with their illnesses, Dick and Gloria accepted their illnesses as part of their life. Gloria’s acceptance

was more on the level of controlling her illness, as she tended to compartmentalise it as something separate from herself. Pamela, on the other hand rejected her Cancer, as it was regarded as an 'enemy' which she could not accept into her life. Acceptance was not on all levels and was balanced with rejection, as participants wanted a choice in how they were to integrate the illness into their lives. The participants found support in their connections with others, although all three participants experienced disconnection from others at times. Illness brought loss to all three participants. Loss was experienced on different levels; physical as well as emotional. The loss experienced was counteracted by gains. All three participants employed strategies to gain control and mastery over their illnesses. These strategies seem to be a complex and unique integration of the individual's personality and attitude towards life, as well as the severity and unique character of the particular illness.

In the case of Pamela, who was diagnosed with Breast Cancer, the severity of the illness forced her to treat it as her enemy. She rejected the illness and developed strategies to fight it on all fronts. When the illness brought depression and threatened her identity she fought back by not allowing the depression to become a part of her. Whereas initially she felt like a 'victim' of the illness she later became a survivor and reached out to others. She also employed the strategy of creating a network of support through friends, other sufferers and family, and her belief in God. Nonetheless, there were times of disconnection and silence as she did not allow others to see her pain. This may also be seen as a strategy to maintain her identity and to distance herself from the severity of the illness. Pamela also employed a strategy of comparing herself to others, whom she perceived as worse off, in an attempt to view her own situation in a better light. She gained as much knowledge as she could about Breast Cancer in an attempt to gain control of it.

Dick, diagnosed with Chronic Fatigue Syndrome, seemed to cope through acceptance of his illness and creating strategies to live with it. He is pacing himself and is utilising his support network of family and employees to make the changes to his lifestyle which his illness demands. However, he is still determined to maintain his identity as a 'driven' and

successful businessman, as he is still involved in his business on a managerial level. Chronic Fatigue Syndrome, which is not a visible illness and is not always medically recognised seemed to silenced Dick. His support therefore seems to be limited to his immediate family, employees and his general practitioner. Dick, like Pamela also used comparison with other sufferers as a strategy to gain control of his illness. Dick searched for knowledge regarding his illness in an attempt to gain control. When he found an article with which he could identify, it motivated him to write his own article about his illness experience. Thus, he used the writing of the article as a way of expressing himself and breaking his silence.

In Gloria's story there seems to be a contradiction. She is coping with her illness through accepting it and doing what is necessary to control her blood sugars, but is distancing herself from the illness by treating it as a total separate entity in her life. This distance has also silenced her. The distance and the silence may be strategies that help her to cope with her illness in a way that fit with who she is. Gloria's coping with her illness is also facilitated by her relationship with her doctor. He seems to give her choices in the control of her illness. She, on the other hand trusts him completely. Gloria, as Pamela and Dick also used comparison to other sufferers as a strategy to gain control.

Although the participants employed different strategies to cope with their particular illness they seem to unite in their determination to celebrate life.

Pamela seems to be amazed in how alive she felt after her surgery. She commented:

En ons het nog gaan swem die aand- jy weet ek is net die vorige paar dae nog 'n operasie gehad, ons het geswem, sy het 'n bal gebring, ons het gespeel...

Dick, although he accepted that he cannot be as physically active as before, had still a lot of plans for the future. He said:

*I am still relatively active if I am well I am going to be active,
I still ride a motorcycle all over South Africa and I am
certain... I am OK.*

Gloria felt that in spite of her illness she can still live life to its fullest. She said:

I love life and I am busy and I enjoy every moment of this...

In the next chapter the themes identified from the stories of the professionals will be discussed.

CHAPTER 6

THE VOICES OF THE PROFESSIONALS

Honour a physician with the honour due unto him for the uses which you may have of him: for the Lord hath created him.

Bible, Apocrypha Ecclesiasticus 38:1

Participant	Dr. P
Age	Early Fifties
Marital Status	Single
Profession	General Practitioner with more than twenty years experience
Special Interests	Trauma, HIV-AIDS, Cancer, Chronic care

Participant	Sharon
Age	Late Forties
Marital Status	Single mother
Profession	Nursing Sister with more than twenty years experience
Special Interests	Chronic care

Participant	Carin
Age	Early Thirties
Marital Status	Married with 1 young child
Profession	Dietitian with more than ten years experience
Special Interests	Diabetes

Introduction

This chapter will explore the main themes related to the professionals' experiences of treating chronic illness that emerged from the texts. The transcripts of the three interviews (texts) are attached in Appendix (iii).

It needs to be noted that the themes that were identified are coloured by the lens through which the researcher interpreted the stories of the participants at this point in time. Therefore, these themes do not claim to represent the only truth for these participants, but are possible interpretations emerging from the perspective of the researcher. These themes identified in this chapter are not exhaustive as another person may highlight different or additional themes.

The experiences of different professionals are represented in this chapter and are connected through the context of chronic illness. Dr. P views chronic illness through the lenses of the physician, who is primarily responsible for the diagnosis and treatment of illnesses. On the other hand, Sharon is the nurse, who is a long-term carer of the sufferer when the illness has so progressed that long-term care is the only option for the patient and his or her family. Carin, as the dietitian whose role it is to educate and prescribe lifestyle changes that most chronic illnesses demands, is the story of the facilitator in this process. Although the experience of chronic illness is viewed from these different professional perspectives (voices), common themes emerged. However, their stories do not only represent the voices of the professionals, but also the unique and individual person behind the profession, and therefore also represent their unique experience.

Roles

Chronic illness seems to demand that professionals need to fulfill different roles. They have chosen to fulfill some roles, whereas other roles are forced upon them by the nature of chronic illness or the person with the illness. The following different roles emerged as themes from the stories of the participants.

The Role of the Professional

Each of the participants was able to define their unique role as a professional within the context of chronic illness.

Dr. P defined her role primarily as the physician, caring for the physical needs of her patients, but is also aware of their emotional and spiritual needs. She said:

Obviously you are there to take care of the patient's needs and when I say the patients' needs, I am talking about their physical needs, obviously I cannot take care of their spiritual needs, but I need to respect possibly what their spiritual needs are...So I think you are there to look after those things, spiritual and emotional needs.

Sharon defined her role as the nurse, the long-term carer of medical patients. She said:

In my nursing training I always preferred medicine to surgery, always preferred the patient care as opposed to the quick in and out and drama of the surgical wards and your patient, your nursing is proper nursing of medical patients.

Carin defined the role of the dietitian as an educator to help people to live a healthier lifestyle. She said:

Om mense te help om hulle eetgewoontes en lewensstyl in terme van gesond eet te verbeter, sodat dit hulle lewenskwaliteit en hulle gesondheid altesaam te kan verbeter.

The abovementioned professional roles seem to be the 'academic' definitions of the various professions the participants represent. However, in their work with the chronically ill, various other roles emerged which will now be discussed.

The Role of the Scapegoat

Often the diagnosis of a chronic illness or the implications of such a diagnosis or the illness itself are dealt with by the sufferer with tremendous anger and it is often the professional who becomes the scapegoat for this anger.

The diagnosis of a chronic and life-threatening illness is often met with anger and it is often the bearer of the bad news who feels the impact of the anger and becomes the scapegoat as in the case of Dr. P. She said:

...like I had one patient- he was very angry with me because he was diagnosed HIV positive and now he is going to church, he is praying everyday and he is livid, because he is still HIV positive. But he is taking it out on me.

It seems that the incurable nature of the illness and the doctor's inability to cure the illness placed her in the role of the scapegoat. After all a doctor is meant to be able to cure illness and if she is not able to do that, the patient may be overwhelmed with feelings of anger, hopelessness and frustration. It is then when the doctor may become a symbol or 'representation' of the illness and the patient directs his or her own anger and frustration towards her. The doctor, through her effort to help the patient, may become a constant reminder of his or her misfortune. Every time the patient visits the doctor he or she is reminded of the illness and the hardship it brought into his or her life. The patient may feel powerless and the only person he or she can take it out on maybe the doctor.

Sharon, as a nursing sister in a long-term care facility where patients often have brain damage due to their illnesses, often has to deal with abuse from the patients. She commented:

Now you have somebody who has tissue death all over various areas of the brain and the loss of inhibition makes him able to slap you because you did not say nicely will you come and bath with me.

For me to be sworn at twice a day, because they had asked me for help is a lot easier to cope with than being the one that has to bath the patient, taking him to the toilet every two hours and feed him...

Even if the patients cannot be held responsible for the ill-treatment of nurses, due to the severity of their illnesses, it is however, the professionals who experience the impact of the patient's anger.

Carin felt that her role as the dietitian often represents for the patient the punishment that his or her illness brought. Dietitians are associated with taking away the good things in life in an attempt to manage illnesses such as Diabetes and Heart Disease. She said:

Daar is definitief die pasiënt wat dit op jou pak en dis half jou skuld, want jy het nou nie reg gehelp nie...

...is dat pasiënte baiekeer sê 'jy straf my.' Dit is vir my sleg.

Jy voel dit, maar jy weet wat moet jy nou eintlik vir hulle sê- 'obviously' is dit nie lekker om te verander nie, maar hulle moet dit doen, so hulle sien jou as die slegte een in die verhaal wat al hierdie goed sê, in 'n mate blameer hulle dan die diagnose op jou.

Carin, like Dr. P, experienced that in her effort to help she became the 'representation' of the illness to the patient and often needed to deal with the impact of being blamed for the patient's misfortune.

It seems that the role of the scapegoat for the patient's anger and frustration is a common theme in being the 'helper' or professional in chronic illness. It also seems that the more severe the illness and the more changes it demands, the more the anger escalates towards the professional.

The Role of the Friend

Chronic illness is life-long and progresses over time. The professional, caring for the sufferer often engages in relationships beyond what is professionally demanded and may become a friend to the sufferer as well as to his or her family members. If the sufferer eventually dies due to the illness the professional may experience sadness, loss and sometimes anger.

Over the years Dr. P built up a relationship with one of her Cancer patients. When she was on leave he was admitted to a facility where he eventually died. She experienced loss and anger as a result of his death. She said:

I was so angry with this doctor at this care facility. Like with these people, Stefan Smith, his name was. He was a fat little tubby American man. 'Stefan, you have to lose weight' I used to say. 'Oh Dr. P if I am fat I know I am fine.' Every year he used to go to the States and bring me a pair of jeans, he was a funny little man and I was very fond of him. And they have killed him...

The death of Dr. P's patient made her feel angry, as she probably felt she was not there for him and needed someone to blame. When someone we care about dies it leaves us with feelings of vulnerability and powerlessness. Dr. P, when she was confronted with these feelings, scapegoats the doctor in the same way her patients often scapegoat her.

Sharon often experience loss if the patients die after nursing them for years. This seems to be a loss of a valued friendship formed with the patient as well as with his or her family. She said:

No, you do as I say you build up a fondness for people in chronic care, because it is long-term. And certainly when you have a patient that comes in for terminal care and passes away a week later you can immediately understand why the ones that we nursed for so many years have the impact that it does, it is not just a patient that has died and

often your relationship build up with relatives comes from their need for reassurance and one has to build a relationship with relatives because they need to build a trust in you to be able to go home at night and sleep.

Carin found that often her follow-up patients will visit her, not for the monitoring of their illness, but to have somebody to talk to.

Ja, partykeer gaan hulle so van die paadjie af en ek het al gehad, dan is dit 'n opvolg pasient, 'even' dan gesels hulle van dit en dat...want hulle kry die geleentheid om met iemand te praat en 'n mens moet hulle daardie geleentheid bied...

It seems that the nature of chronic illness demands from the professional more than only being a physician, nurse or dietitian, but becoming a friend as well. Perhaps, this has to do with the blurring of boundaries between the professional and the patient, where they now interact together as humans.

The Role of the Expert

The role of the expert is traditionally assigned to the professional due to his or her expertise acquired through training and experience. This role is also assigned to the professional through the expectations of the patient. Sometimes the professional will accept the role and at times may decline it. The professional may also experience that his or her expertise is challenged.

In chronic illness, experience seems to teach the professional to accept that sometimes he or she is not the expert and the illness itself defines the management or treatment. The professional in times like these needs to decline the expert role and give the choice to the sufferer as in the case of Dr. P. She said:

I think that a lot of illness anyway in medicine is, either you can manage it, you can't necessarily cure it, if someone got a boil you can cure it, you know, I mean, there is some

diseases you can manage, like hypertension and diabetes and then there is some diseases that you will manage until the end of that person's life, because that disease you can't even control necessarily.

I think most of the time what doctors need to realise, most things you can't cure them, most things they (the patients) are not going to listen to you, they not.

Chronic illness seems to present the professional with a paradox; his or her role is defined as being the expert, but the nature of chronic illness challenges this role.

Carin felt that it is often the patient who forces her into the role of the expert. This is a difficult role bearing in mind the nature of chronic illness as it is life-long, uncertain and often unpredictable, not only for the sufferer, but for the professional as well. Being forced in the expert role in the context of chronic illness may set her up for failure and then consequently blame by the patient for not fixing the illness. She commented as follows:

'Ja, ek gaan nou die medisyne drink en so eet en dan sal dit weg gaan?' Definitief en 'kan jy my nou nie reg help nie, hoekom kan jy my nou nie gesond maak nie-ek betaal jou, ek kom sien jou sorteer my uit...'

Dis moeilik, maar die ding is mense soek 'instant results' – hulle is nie reg om dit te kry nie, maar hulle wil die 'results' hê...

Yes, yes hulle sien jou as die 'expert' en hulle wil hê jy moet vir hulle die kennis gee en presies wat hulle prakties moet doen en baie keer as hulle kennis het, gaan dit meer oor die praktyk.

It seems that the expert role is also linked to the unrealistic expectations from patients. Patients seem to demand 'fixing', which is an impossible task in the context of chronic illness. Again, chronic illness places the professional in a paradox; meeting the expectations of their professional role as the experts in illness is not always possible in the context of chronic illness.

Although Carin experienced the pressure of being placed in the expert role, she also felt that this role is challenged by patients and others claiming the expert role of the dietitian. She said:

Ja, jy weet, 'n ma is die 'expert' van haar gesin se voeding en elkeen ag hulle self as 'n 'expert' en hulle hoor by hulle ma en hulle ouma en... En dan is daar hierdie mense wat intensief die Internet en alles bestudeer en hulle weet partykeer 'even' van goed waarvan jy nog nie eers gehoor het nie, nie dat dit noodwendig goed is wat nagevors is nie, maar dis ook moeilik omdat dieetkunde so wyd is en 'n mens nie noodwendig spesialiseer nie, jy het nie die tyd om in detail na elke liewe dingetjie te kyk nie, van elke liewe ding 'n studie te doen nie en al die nuutste goed uit te vind nie. En dan kom iemand na jou toe en dan voel dit partykeer sjoe, ek weet nie...

Carin's feelings seem to be ambivalent regarding the expert role. On the one hand she experienced pressure being the expert and on the other hand felt that this position is often challenged and sometimes quite legitimately.

Experience taught Carin that she as a professional sometimes has to accept her limitations and to accept that her advice at times may be rejected. She said:

Ja, absoluut, ons kan nie 'n 'magic wand' swaai en hulle is gesond nie. En ook omdat jy nie in beheer is nie, m.a.w. jy kan vir hulle presies sê wat hulle moet doen, maar hulle gaan dit nie noodwendig doen nie...

Carin seems to have the power as the expert, but no power to actually change others or make them do something.

Sharon, does not seem to experience the problems associated with the role of the expert. Nurses are traditionally seen as the care-givers in the hierarchy of the medical professions. Whereas the doctor and dietitian are perceived as the experts, the nurse is

perceived as the carer. Therefore, the expectations of patients from the nursing profession seem to include that of caring and not necessarily 'fixing'. Sharon seems to accept the role of caregiver and feels that nurses are better equipped to deal with chronic illness as they are not placed in the role of the expert. She commented:

Yes, I think it is harder for doctors (to deal with chronic illness) and I also believes it goes back to the training ethic that they should fix people and make them better, where we (nurses) for instance just to illustrate to you why I feel that way is that I find of the team, the multidisciplinary team nurses are the poorest rehabilitation (fixing) people, we have to be almost retrained into rehabilitation. Because we taught to do for (care) and you almost feel a bad nurse if you are not doing for patient, because I think, ja it is easiest, not easiest, but I think it comes more naturally to the nurse to deal with incurable diseases.

It seems that the participants, except for the nurse tend to move in and out of the expert role which is traditionally assigned to them. The nature of the professional role and the expectations of patients seem to place the professional in this role. Chronic illness, on the other hand, challenges the expert role, which forces the professional at times to decline being the expert. It seems that experience has taught the participants when to accept the expert role and when to decline it.

The Role of the Rescuer

Dietetics, nursing and medicine are often referred to as the 'helping' professions and the occupiers of these professions therefore perform the role of the rescuer or helper. Each of the participants accepted this role.

Dr. P found her motivation for the helping of others. She said:

Maybe I am a healer, I think. I hope to think, I hope I can help some of the people, some of the time, but that is all I can hope for.

For Sharon, her work with the chronically ill seems to be an extension of the person she perceives herself to be; a helper. She said:

I have done a lot of soul searching that I actually realised that if I did not carry on who I am, which is this person who needs to do for others, that is who I am, I actually would not like myself, anymore. So at this stage, I don't actually think that I want to change. I really don't, I feel I have reached a place in life where I am at peace with...

We have not chosen an easy road, have we? We have chosen the road of people.

For Carin being able to help people is the motivation for her to carry on with her profession. She said:

Ag maar dit is 'obviously' dat ek daarvan hou om mense te help. Dit is vir my 'rewarding' om mense te kan help.

Helping others seems to be the common factor in why the participants chose their professions in the first place. To be able to help or make a difference in someone else's life seems to make their daily work bearable and meaningful.

The role of the rescuer does not seem to go hand in hand with the profession itself, but seems more to be a continuation of a role acquired from childhood or other spheres in life. Thus the rescuer role which forms part of their professional role coheres with who they perceive themselves to be.

Dr. P felt that she was a rescuer from a very young age, as she grew up in an alcoholic home. She commented as follows:

Yes and I think that is where I come from to a certain extent, because I was always rescuing my mother...but, yes I was in rescue mode from when I was very young.

I think a lot of doctors come from situations in their childhood where they become the caregivers or they are the rescuers.

Sharon also saw herself as a rescuer from a very young age. She describes her childhood as follows:

I think it is a personality thing, now I certainly traced back and I am not one that says, oh it was my childhood, but I have traced back my place in the family and I come from a complicated family, we were ten kids, that in my family I needed to be one of the givers for the whole complex thing to work. I needed to be that one that would sleep on the floor rather than to cause a whole big conflict over it.

Carin felt that she acts as the rescuer in her interpersonal relationships outside the consulting room. She said:

Ek is geneig om 'n 'rescuer' te wees, ek sal byvoorbeeld, ek kan dit nie hanteer as daar struwelinge is tussen mense in terme van verhoudings nie m.a.w. dit grief my as mense kwaad is vir mekaar. Ek kan nie of dit nou ek wat kwaad is of heeltemal twee ander mense in my gesin – 'I want to resolve it'...

To be able to fulfill various roles seems to be a requirement in working with chronic illness. Some of the roles, such as that of rescuer or helper seem to fit with the nature of the participants and are experienced as rewarding and meaningful. On the other hand being branded as the scapegoat or losing a long-term patient/friend are emotionally costly. The expert role seems to be met with ambivalence and is dictated by various factors such as society's expectations, the nature of the illness and the patient.

Needs

In their interaction with patients suffering from chronic illness, the participants seem to be very aware of the needs of the patients. These needs are often in conflict with the roles

assigned to the different professions and require professionals to blur the boundaries between their professional and private worlds. Sometimes the needs are overwhelming or are on a different level to what the professional is either equipped or supposed to handle as defined by the specific profession. On the other hand, the professional herself has also got needs within her relationship with her patient.

Needs of the Patients

Dr. P is very aware of the fact that patients' needs are not only physical, but spiritual and emotional as well. She commented:

...illness is owned by somebody, who has got their own life and their own emotions and their own needs and their own other problems.

...you know everybody has got different spiritual needs and respect those and often to a great extent, a very great extent is their emotional needs.

I think some doctors found that they don't like it if they feel a patient is leaning on them emotionally. No you are not there to solve a patient's emotional needs, but I think you have to be there, when they sad, when they frightened, when they feel helpless, you have to be there, its part of the treatment and treatment does not necessarily mean healing.

It seems that the professional in dealing with chronic illness has to give more than only his or her medical expertise; he or she needs to give a part of themselves. Sometimes you have to fulfill roles you are not necessarily professionally equipped for. Dr. P said:

...you have to be a bit of a psychologist, I think

In the case of Sharon, there was not only an awareness of the patient's needs, but also the needs of his or her loved ones. She said:

...and often your relationship build up with the relatives comes from their need to build a trust in you to be able to go home at night and sleep.

And it is a fight I constantly pursue with the nursing staff, that we preserve their dignity, because there is loss of dignity in the loss of mental function and I found that very, very hurtful not only for the patient, but also the relatives who walk in on these moments where you dad who was never like that is doing something that, that's not really socially acceptable.

Carin is very aware of the emotional needs of patients being diagnosed with a chronic illness and found she often has to help the patient through the process of understanding his or her illness which means she needs to extend her narrowly defined role as an educator in nutrition to one that includes meeting the emotional needs of her patients. She said:

Baiekeer is dit ons wat die tyd moet spandeer om dit te doen, want ek voel net ek kan nie vir iemand verduidelik wat om te doen en sy lewe te verander as hy nie verstaan hoekom nie. So baiekeer spandeer 'n mens tyd daaraan en my 'worry' is altyd gaan die persoon weer terugkom, so ek het dit altyd in my agterkop, jy weet, so ek wil altyd half te veel as te min gee, want ek weet nooit of die persoon weer gaan terugkom nie en ek weet nie of dit verkeerd van my is nie, moet ek eerder maar min gee en hoop hulle kom terug- moet jy maar eerder net konsentreer op die diagnose of die aanvaarding?

...is die eerste deel van die konsultasie spandeer jy nou aan die emosionele sy of die diagnose of die komplikasies of 'what ever' verduidelik, maar op die ou end is daar so min tyd oor om fisies te sê vir die pasiënt oor wat om te doen dat jy die laaste stuk eintlik aframmel en te veel informasie in 'n kort tyd gee en dan dink jy 'oh sherbet' gaan die ou enigets kop of stert uitmaak...

Presies en weet jy wat, ek het al en jy weet dan probeer jy, soos jy sê 'all to cover everthing' en dan op die ou end het ek al gesien dan probeer ek partykeer hou by

*vreeslik 'basic' en min goed of 'even' gee al die detail,
maar dan sê die pasiënt vir my 'nou OK wat moet ek
eet'*

It seems that all three participants are sensitive to the needs of their patients and by responding to their needs they often move out of their professional role and become the supporter, the crutch for the patient to lean on. This may be in conflict with their professional role, like in the case of Carin who ends up spending time with her patients on the emotional impact of their diagnosis, instead of giving merely nutrition education. The needs of the chronically ill patient seem to push the participants beyond their professional boundaries and they seem unable to stay disconnected personally from their patients.

Needs of the Professionals

A need for acknowledgement and a need for self-preservation emerged from the stories of the participants.

Need for Acknowledgement

The professional who is in a relationship with the sufferer of chronic illness seems to need acknowledgement from the sufferer that their interaction is meaningful and is significantly contributing to the well-being of the sufferer. Knowing that they are helping or actually making a difference in the life of someone else is rewarding and motivating for the professional. This acknowledgement is the factor that makes their work meaningful to them.

Dr. P felt that helping others was rewarding in itself, but at times needed acknowledgement for her efforts. She commented:

*I hope I can help some of the people some of the time,
but that is all you can hope for.*

You know and you sometimes need that. We all need stroking.

Sharon experienced her days as rewarding when seeing that her efforts were meaningful to her patients. She said:

If I have a day at work where I am given time to actually mean something to somebody that was in need then I had a good day...For a patient here, for me to see that it actually made a difference in an otherwise very sad life- its all I need to call it a good day.

Carin also experienced her work as rewarding when she got good feedback from her patients. She said:

...ek dink in vergelyking met baie ander professies, is daar darem wel 'n mate van 'reward'...jy weet 'work reward', omdat jy van mense hoor dat...dat ek iemand kon help.

... baie keer sien jy dit nie, jy hoop maar jy sien dit en jy hoop nou maar met die persoon het dit goed gegaan en dit het al baie keer gebeur dat ek regtig iemand na 'n lang ruk gesien het en dan het hulle baie goed gedoen en dan het hulle en hulle het bereik wat hulle moes, jy weet net nie daarvan nie. En dan is dit baie keer is dit lekker om te hoor 'o ag jy weet'...

Need for self-preservation

The professional is a witness to the suffering of others and needs to be sensitive to the needs of his or her patients. However, professionals are humans with their own hardships and struggles and therefore at times need to protect themselves against suffering with others. From the stories of the participants it seems that they developed strategies for self-preservation.

Dr. P realised the importance of her own well-being in her work and developed strategies in self-preservation. She commented:

You do visualise it, quite a bit. I sometimes write things down, like things that I found a little bit hardcore on my soul, I read quite a bit, I try and do nice things, you know...

I have to safeguard my own well-being, you know.

Sharon acknowledged that she at times experienced the suffering of her patients as overwhelming and therefore went through patches of 'bluntness' or detachment in an attempt for self-preservation. She described it as follows:

There are days when I come to work and see the facility as people who don't come here often, see it. How sad it is. I think that we go through periods where your self-preservation kicks in and you see this, but you don't see. You see them as I am coming in to give medicine, look after them, make sure they are comfortable, make sure all is fine, but you are holding back from letting it... and then for what ever reason you go through patches that you cannot do that.

Sometimes the need for self-preservation involves seeking assistance or help. Sharon said:

And I do believe that it is just part of the health profession. We are not dealing with the cost of sugar and milk and we are or do I think see very, very sad things. Very distressing things and whether you want it to or not there is that part of you that absorbs it and you need to work through it before you can put it in its right place I suppose. So, ja I, I try as far as possible now to work through issues so that you don't become a difficult person either to live with or to work with and I say that's why in the years on and off I have gone to see therapists for a little while until I

almost sorted it all out in my own head and you feel stronger and you cope better in a given amount of time.

The need for self-preservation may also affect her loved ones, as Sharon sometimes needs to withdraw at home to the dismay of her children. She said:

I go home and I ...I am actually not bad tempered, I will withdraw, which upsets them and then they question and you almost like those dogs that wants to go to the corner and lick your wounds and that is when I will snap at them and they become quite resentful of that.

Carin realised that she needs to restrict the number of patients she sees per day as she finds the consultations exhausting and needs time to reflect.

...en op die ou end dan is dit vir my net so erg, ek kan naderhand nie eers meer onthou hoe hierdie persoon gelyk het nie, want jy het net soveel mense- dit was net so 'n 'overload' van informasie en mense en hulle probleme en ' issues' dat dit is asof ek net nie meer kan fokus nie... maar ek dink as 'n mens die hoeveelheid mense wat jy op 'n slag sien per dag beperk dan raak dit 'n minder uitmergelende proses.

It seems that all three participants experienced that the intensity of their involvement with their patients fluctuates. It does not seem humanly possible to be constantly open and vulnerable to the high intensity of suffering of others. This does not mean that they are not doing their jobs, but at times need to withdraw in an effort to cope. Strategies for self-preservation varied from detachment, to diverse ways of expressing their feelings, seeking professional help and limiting encounters with patients.

Boundaries and Blind spots

Being confronted at times by the overwhelming needs of their patients, the professionals have to put some boundaries in place in an effort to preserve and care for themselves as well as to fulfill their professional role. Setting up boundaries in the relationship is difficult as it challenges the professional's natural human instinct to care and help. All three participants acknowledged their human weaknesses, the impact of their background and having their own unique personalities. These result in their own blind spots – patients and conditions that they just do not want to see or treat.

Dr. P found that some patients do not respect the boundaries of the doctor-patient relationship. She sometimes needs to put these boundaries in place, for her own personal well-being, but also to fulfill her role as physician. She commented as follows:

They will devour you. They will devour you.

And sometimes they want to feed off you. You can't allow that.

Well, I feel it. I know when someone is feeding off me. I know when they feeding off me and I will put a stop to it.

You can't buy into that, you will drive yourself off the edge; you won't be able to do this job.

...but sometimes you have to draw the line if people are really rude I will actually ask them please go and see someone else. Because you not obliged to put up with people that are damn abusive.

Carin found that she tended to take all the responsibility of her patient's progress or lack of it on herself. When she was pushed to the limit she created a boundary which was to sometimes hand over the responsibility of the illness to its sufferer. She said:

Ja, in 'n mate voel jy verantwoordelik, jy voel jy wil vir hulle verduidelik – OK, jy het tien teen een water,

jy hou tien teen een water terug of jy weet, jy probeer half namens die pasiënt 'n rede soek of 'n verskoning soek hoekom nie gebeur het wat moes gebeur het nie, want jy voel verantwoordelik

Ja, en ek bedoel daar en ek het dit ook al vir pasiënte gesê, jy weet, ek sê vir jou dit is wat jou gaan help, maar dit is nog steeds jou keuse of jy dit gaan doen, jy weet as dit iemand is wat baie negatief is dan maak jy dit duidelik, ek sê nie nou vir jou jy moet nou gaan en dit gaan doen nie, die 'ball is in your court'.

Although Sharon, also found the needs of her patients at times overwhelming, she did admit struggling to put up boundaries, even after all her years in nursing. She said:

Oh yes, I think the individual's reaction to chronic illness is individual. Demanding, very demanding...

Oh I am not good with that. These personality traits never are. But I am better, I am better than I used to be and I believe that is an area that I can work on, not trying to change, but stop things like burnout and needing anti-depressants and I think if you have good boundaries in place you don't reach those lows in life and I am working very hard on it at the moment and to do it in an assertive way that is not hurtful

It seems that boundaries became necessary when the participants felt that they were taken advantage of. Boundaries seem to be necessary when the impact of the interaction between patient and professional becomes uncomfortable for the professional.

The participants were able to acknowledge the existence of blind spots in their work with the chronically ill. Blind spots may result from a personality clash between the patient and the professional. Other times it may be due to the attitude of the patient or sometimes it is a specific illness or condition the professional just does not like treating.

Dr. P felt that would she rather not treat patients whom she perceived as hypochondriacs. She also does not like treating patients with Chronic Fatigue Syndrome (yuppie flu). She said:

Ja, of cause you get days where you feel –oh God what are you telling me. Hypochondriacs, I am not good with. I am not; I am not tolerant with them.

Like these people that want to have yuppie flu, I just say to them ‘look there is two schools of thought. One school of thought feels that there is such a thing and one school of thought feels that there is not. And I belong to the school of thought that believes that there is not.’

For Sharon her blind spot is sometimes just a patient with a certain personality type or style that she does not get along with. She commented:

But I would be a liar if I said I have not been faced with the real thing of the human factor, I just not like that patient and your professionalism is truly challenged and often it is not because of behaviour, it is often like in life, it is just a personality clash, you just do not like their style. And that is once again; who we are comes into it.

Carin felt that certain patient’s attitude towards her may be defined as her blind spot. She said the following:

Ek sou sê pasiënte wat ek nou moet sê waar ek regtig ongemaklik gevoel het en nie van hou nie is tien teen een pasiënte wat my as persoon aangevat het- vir my, wat ek bedoel wat half, ek probeer nou aan ‘n geval dink, ek bedoel ek dink aan mense met wie jy soveel moeite doen en jy spandeer regtig tyd en moeite en so en dan sal die persoon agter jou rug of teenoor jou persoonlik half sê jy het eintlik niks vir my gedoen nie, jy, my probleem is nie opgelos nie, jy is niks werd nie of van ek het my geld gemors of ek het my tyd gemors, in die ‘mean time’ het jy soveel baiekeer is dit juis iemand wat vir wie jy soveel moeite spandeer het of iemand wat sê ‘OK, ek skuld jou geld maar ek gaan jou nie betaal nie, want ek het niks hier uit gekry nie.’

It seems that all three participants, through experience, recognised their blind spots. From an ethical perspective it is important for the professional to acknowledge his or her blind spots and to communicate these to his or her patients, if appropriate. For example, in the

case of Dr. P, she communicates her feelings on Chronic Fatigue Syndrome, which gives the patient the opportunity to seek another physician who may be a better fit. However it would be more difficult if it is a personality clash.

Differentiation vs. Integration

It seems that the professional working with chronic illness needs the ability to sometimes differentiate between the patient and the illness, when it is important to do so. At other times, the situation may demand from the professional to integrate the person with the illness. Differentiation seems to be required when the professional realises that it is the illness which is the cause of the patient's behaviour. On the other hand, integration of the patient and the illness is necessary in order to view the patient in totality, as a physical, spiritual and emotional being

Differentiation

Differentiation is required when the feelings of hopelessness and frustration as a result of struggling with illness manifest in anger, which is often directed at the professional, as in the case of Dr. P.

Dr. P realised that often the anger that is directed at her, actually has very little to do with her, but is more a manifestation of the process the patient is going through in dealing with his or her illness. She said:

And they sometimes get angry with you as the doctor. But I understand that it is not about you. It is not about me.

Sharon found that sometimes the very demanding behaviour of a patient is often the result of the illness and not necessarily just the whims of a demanding person. She said:

I found that patients like that, they are demanding, the bell rings every five minutes and they want to, they want

somebody close by all the time, but very often when I have monitored it and watched the situation, it is so regularly based on fear-that I would say is pretty real, in a situation like that. But especially with lung disease, I found this fear a huge factor of behaviour and I often thought, well if I was in a room all on my own and I could not breathe I [would]also be petrified.

Carin, through experience learned that often her patients' 'failure' to comply with the prescribed lifestyle changes did not mean that her input was disregarded or was a rejection of her or her advice. She commented:

Jy weet 'n ervaring soos dit het 'n mens laat besef dat baie keer het dit absoluut niks met jou of niks te doen met die 'prescribe' wat jy vir die persoon gegee het nie.

The professional, treating chronically ill patients seems to need this ability to differentiate between the person and the illness in an effort to fully understand the process the affected person is going through. The reaction of the patient to the professional is often not personal. It is 'not about you' and your feelings, but about the struggle of the patient to deal with his or her illness. However, integration between the person with the illness and the physical results of the illness is also required. It is specifically in this context that the participants felt the limitations of being trained in the traditional medical model.

Integration

Integration of the patient with the illness is necessary to view the illness not as a separate identity, but owned by someone, who has not only physical needs, but emotional and spiritual needs as well. Participants felt that the medical model focuses only on the physical symptoms, in other words, the focus is on the illness and not enough emphasis is placed on the person with the illness. It is in this context that integration between the patient and the illness is required.

Dr. P felt that her training did equip her to treat the physical symptoms of the illness, but did not prepare her for the needs of the person owning the illness. She said the following:

They only train you in the actual disease or the disease process that you dealing with. Not the person, you deal with the illness or that is what they teach you, but they forget to teach you that, that illness is owned by somebody, who has their own life and their own emotions and their own needs and their own problems.

Sharon, who is involved with the long-term care of patients, found it very difficult not to get involved with her patients and keep the focus on the illness, as prescribed by the medical model in training. She said:

And unfortunately it is a relationship, well fortunately is built between the nurse and the patient in long-term care. The teaching that I have got as a student that you don't become involved with your patients is extremely difficult to apply to long-term care.

It seems that Sharon's ability to integrate the patient and the illness came naturally as a result of her work as a carer of long-term patients.

Carin, in reflecting on her training, felt that although there was an attempt to incorporate psychology in her course it was never effectively integrated with the subjects on nutrition. She also remembers how as a student she and her colleagues used to label patients according to their diagnoses, forgetting the person who owns the illness. She commented:

Nou kan ek vir jou sê ons het sielkunde gedoen as 'n vak en dan het ons voeding gedoen as 'n vak, maar ons het nooit die twee geïntegreer nie. Yes, so die sielkunde of die menswees nooit vreeslik toegepas in dieetkunde self.

En dis half 'n voorbeeld van waar 'n mens die menswees inbring. En op sulke goed het jy glad nie gekonsentreer nie op universiteit nie. Dit was 'n diabeet en dis hoe jy dit

behandel en ons het altyd gespot, want jy praat altyd, jy praat nie van meneer so-en-so nie, jy praat van die diabeet en die ou met die nierversaking en dis kankerpatiënte...

It seems that all three participants developed with experience the ability to acknowledge the person behind the illness. This seems to be a skill acquired through the teaching of their patients and not as a result of their academic training in the medical model.

Making Meaning of Illness

The participants witnessed the pain and suffering of others. In order to do this work they need to make meaning of the suffering they often witness. In making meaning of illness and the consequent suffering to human beings, the professional is often challenged with moral issues and questions.

Dr. P is often challenged with the question of ‘why do people get ill and why do they have to suffer?’ Confronted with this she developed her own understanding of suffering. She said:

I say to them (the patients), I mean I am not very religious, but I think that is just life, you know. God is not punishing anybody. It is just, it can happen to anybody. It is like why does somebody get murdered, nobody deserves to get murdered, it just that is what life is about. Unfair things happen to good people. That is life.

But I don't believe that you get punished for things that you have done in your life and that is why you get ill.

But like I say to them, we don't know. It is like someone, I had a patient I look after, and he has been bedridden for the last fifteen years with MS. I have looked after him in Haven's. He can't sit by himself, he can eat sloppy sort of food, he's got a catheter, all he can do is lie in his bed and watch TV, he can't walk, he can't sit, he can't move, he is like quadriplegic, almost from it. And you know one of the

nurses was very upset one day, nursing him and said to me- 'what is the meaning of his life, why is he alive, what is the purpose of his life?'- And I said maybe the purpose of his life is to teach other people compassion. I think we all start questioning what is the meaning of our life, it is pretty simple stuff, maybe his is to teach others compassion.

It is hard to put in words, you know. I don't think death per say is a frightening experience I think what you fear is how we going to die. Will we have pain, will we be tortured, you know, that is what we fear, but what is on the other side, nobody really knows. I mean the churches may tell you if you believe in God then you may...they don't know that either, they don't, but if that comforts somebody, that's fine.

Sharon, who is also confronted with the same questions, went through a process of making meaning of all the suffering she witnessed over the years. She was often confronted with her own moral viewpoint regarding human suffering. She commented.

That was not the only time that I was asked possibly four or five times over the years why we do what we do, because there is no quality of life there is no and once again it has been a road of many little pathways to reach something I found I can live with. At one time I have experience a lot of anger that I actually did not recognise for a long time about why, why does this happen to people, why don't they die? You have this bad accident and you lose half your brain on the road, why then you find the answer, oh it is the paramedics fault, now blame all the paramedics, then you talk enough to people and they say your son is in a accident tomorrow, you don't know what the end result is going to be- are you going to say leave him to die or are you going to say fight for his life...And that squashed that theory for me. Then I started to think about euthanasia, because within your worst mental psychiatric or dementia type illness patients often have lucid moments and I had a patient here that have asked me repeatedly on night duty to put a pillow over her head. And you know it sets obviously you try to answer correctly to such a sad request and it sets your thinking going and I actually become totally against euthanasia within this work because I believe just what you have said that we don't know the purpose of any of what we see in life. It is to teach those around about human courage that is just

beyond your human capacity to understand you see in chronic illness...

It is huge, humbling to be around, so ja I answer people like that there must be a purpose and I don't have the answers and it is not to me to have the answers, but I believe as for long as we are preserving not only human life, but trying to preserve comfort and human dignity that is why there are places like this and this kind of care. I don't have the answers and I don't seek for it anymore, but I do believe in what we do here, very strongly. I think once again it's become a more peaceful area for me with the spiritual growth that I have managed to get through brought about possibly a lot by the work that I do. I truly believe that you do let go and let God...

Carin's story did not represent a similar struggle in making meaning of the suffering of others. This may be due to the role of the dietitian, who has less contact with the patient in comparison with the doctor or nurse, who are usually called in at times of pain and suffering. For Dr. P and Sharon, who are often the witnesses to the severity of illnesses, it was important to work through the issues of human suffering. It seems, although they do not have all the answers, they have accepted suffering as part of living and their role in relieving the suffering of others, where possible.

Recognising the Power – The God Complex

Health professionals, especially doctors are often accused of having a 'God Complex' meaning that they have the power over life and death. Their decisions may sometimes determine who receives treatment and who does not, or who has access to facilities and who does not. It seems that from the stories of the participants there is an awareness and acknowledgement of the power they hold in dealing with sufferers of chronic illness, who are often vulnerable.

Power through Knowledge

Sometimes the power assigned to the professional comes from the intimate knowledge he or she shares with his or her patients. Dr. P found that she became the gatekeeper of a family secret and that the information she held had the power to destroy a whole family as well as leave a man to die alone. She however used her power to protect both the patient and his family. She said:

...but when he was diagnosed with HIV, when I diagnosed him, first he came with Herpes and he has been a bit of a naughty boy in his life, I love him to bits, he is a real character, he is in his sixties, but I just said to him you cannot walk this path alone. This was like nine, eight years ago, I said you cannot and I said you and your wife has slept in separate rooms for fifteen years, she does not need to know how you got it, because he got it from a black prostitute and I concocted some story that he helped some guy that fell off a crane at his work... You know what he is a hero in her eyes; the family is supportive of him. Do they really need to know, how he got it? No, I don't believe that they do. I know it is a bit of a lie, but they don't, they don't need to know that for them, they don't need to know he is sleeping with black prostitutes and he is not doing it any more and he needs their support.

Power in Helping

Great power is assigned to helpers who help those who are made vulnerable and helpless due to the progression of their illness.

Sharon is very aware of this power and the possible abuse it may cause. She said:

And that distresses me terribly, because within our professions we hold tremendous power and if it is abused it is frightening.

You are abusing the power you have over this person when you leave him sitting in their own faeces for four

hours and it is so important to recognise that that is what is happening, literally.

Acknowledging the power of the professional seems to be an important factor as it may easily be abused or used for the wrong reasons.

Dr. P felt that some of her colleagues are oblivious of their own egocentric needs that could lead to an abuse of power. She commented:

I think they (doctors working in terminal care) do a lot of good work, don't get me wrong, but I think a lot of people that work there, work there for the wrong reasons. They stroking their own egos and that's all. And you have to be careful with that in this profession.

It seems that both Dr. P and Sharon realised the power their professions hold. However in the case of Carin, she seemed to experience a loss of power. She felt her power position as the gatekeeper of nutritional knowledge is challenged from various fronts, the media, other professions and sometimes the patients themselves. She commented as follows:

...wat vir my in die agterkop meer 'n 'issue' is, is dat voeding raak so half 'n Jan Alleman ding, jy weet, elkeen ag homself as 'n 'expert' in voeding en ek dink dit is meer iets wat my nog altyd gepla het.

Empathy

A central theme in the participants' stories was their ability to show empathy for their patients. Empathy refers to the ability to understand the feelings and experiences of others from their point of view. This ability seems to emerge from the professional's own lived experience as well as from insight into the nature of chronic illness. It appears that through their own experiences as well as through their patients' experiences they developed an understanding of the nature of chronic illness. Apparently this was not theoretical knowledge but was based on real experiences and real people.

Empathy through Lived Experience

For Dr. P three significant episodes in her life moulded her understanding of what a chronically ill person is going through.

Dr. P developed Nephrotic Syndrome at the age of ten. Nephrotic Syndrome is an illness that affects the kidney function and is often treated with high dosages of steroids. In some cases it may be acute and in other cases chronic. She described her experiences as follow:

I think what also played a big role in my life is when I was ten I got Nephrotic Syndrome and I was off school for six months and I was on medication till I was twenty one. You know, I know what it feels like to have to, I remember going to school every morning my brother had to run in with a sample of urine to the doctor and in those days they did not have a urine dipstick, they burnt it with a Bunsen burner and I can remember looking at my urine, I was ten years old and suddenly over the Bunsen burner-it clotted like egg white, solid you could take it out of the test tube and those kind of things I have never forgotten, you know.

She also remembers the feeling of a loss of identity. She said:

I was put on huge dosages of cortisone, I went back to school after six months and the teacher said to me 'here, are you the new girl, what is your name?'

Yes I was on big doses of steroids. Huge and the teacher did not know who I was, that freaked me out, hey. That really freaked me out.

The possibility of dying from a life-threatening illness also became a reality for her and therefore she feels that she can talk to her patients about the fear of dying. She said:

Oh, I tell you why I have accepted it (dying), because I got Staphaloc... start again Staphylococcus septicaemia myself in 1989 and I was in the clinic for three weeks and I was very close to death, I lost 15kg, I had two laporotomies, they called

my parents from Cape Town and I had a near death experience. You know, people think that is nonsense it's the omni., but it is definitely not. And it is a life changing experience, well it was for me and I think everybody who has experience that, it is a life changing experience and for myself I don't fear death, I don't feel uncomfortable talking about death, I don't feel uncomfortable asking somebody how they feel about it.

She also felt that through her own experiences of trauma, when her brother-in-law was murdered, when she worked with sexually abused children and when her life was threatened by robbers; made her sensitive to the trauma of others. She said:

You know, my brother-in-law was murdered, I worked as a district surgeon for two years, I have worked for the child protection unit, with sexually abused children for nine years and this was the weirdest thing when I had that robbery, it was four years ago, it freaked me out, hey. They have tried to kill my dogs and threatened my life although nothing happened to me, all these other stuff just came flooding back. I understand where she (the patient) is at. I could say to her you are feeling this and this and she said how you know that.

Sharon's own hardships in her personal life possibly made her more sensitive to the suffering of others. She commented:

...because my personal life is been, I have been a single parent for many years and it has been a stressful time.

Carin, did not experience a chronic illness herself, but felt that having a mother as well as a mother-in-law with chronic illness helped her to develop a better understanding of the process her patients were going through. She said:

Ek dink nie so nie, ek dink mens het dit eintlik net as 'n mens self 'n chroniese siekte het. Ek dink dit gee jou 'n beter idee as jy iemand naby aan jou aan jou familie, iemand naby jou het, jy sien wat is die 'everyday' goed waarmee hulle sukkel en wat hulle gevoelens en hoe tree hulle op, jy weet ek dink dit is anders as om dit net vir

jouself te probeer indink as wanneer jy dit fisies sien of wanneer jy dit self ervaar. Ja, dit maak 'n mens half...as om net te sê gaan doen dit nou maar net dit, jy besef nie eintlik wat dit alles inhou nie, jy weet daai feit van wat dit werklik is, veral as dit 'n lewensbedreigende siekte is, dink ek dit is 'n 'issue'.

Dis ook hoe ek kan sien jy weet spesifiek in terme van dit wat hulle nou het, jy weet hoe hulle optree in terme van hulle siekte en hoe hulle en die moeilike ding waardeur hulle gaan en hulle sal byvoorbeeld diabetes as 'n voorbeeld partykeer absoluut goed wees en reg eet en alles en dan kom hulle net op 'n stadium hetsy of dit as gevolg van depressie of moedeloosheid of so –'ek gaan nou iets lekker' en dis maar waardeur pasiënte gaan, jy weet daar is stadiums wat hulle regtig goed doen, wat hulle moet en dan is daar ander stadiums van 'ag ek gaan ' anyway' dood gaan, kom ek eet wat ek wil'

It seems that the participants' own hardships and vulnerabilities equipped them to understand the suffering of their patients. The participants' own life experiences seemed to have moulded them to be able to have empathy with their patients.

Empathy through Knowing the Nature of Chronic Illness

From the stories it may be concluded that the participants developed insight in what it means to be diagnosed with a chronic illness as well as living with it. They were far beyond a point of having mere theoretical or academic knowledge of the nature of chronic illness; it seemed as if they knew.

Understanding the chronic nature

Dr. P showed great understanding for what a patient with a chronic illness, such as cancer is going through. The process of chronic illness is never-ending; from the point of realising that maybe something is wrong, to the actual diagnosis and treatment and, thereafter the on-going follow-up, the patient is never freed from the anxiety brought on by the illness. Dr. P described the process as follows:

...because they tell themselves what if I have got x y or z, but you know, you take something like Breast Cancer, I mean it is a shock when you got told yes you have a lump in your breast and it could be Cancer, then you go and have a biopsy and yes and it is Cancer, but you know the reality of the whole process only starts to sink in when you start with your chemo, then your hair starts falling out and now you have been six months on chemo, you had your partial mastectomy or mastectomy, your friends all think oh well six months down the line, she is fine, but meanwhile it is different things you are facing all the time and once you had your chemo, maybe you have to go on radiation and then you sit and you wait and every six months you have to say let me go and hear if I am still in remission or not.

Understanding the fear

Dr. P also understood the fear, especially the fear of the unknown that a chronic illness brings into a sufferer's life. She responded as follows:

I think often they will know it is not curable, they need your support, they need someone they can talk to in that they can get explanations for things, like I am just thinking of a patient now, I am sure she has Melanoma, I am sure she has, she is very frightened of this diagnosis, but I mean the diagnosis has not even been made yet.

Sharon also understood this fear of the unknown and the confusion that an illness may cause. She explained:

I found that where the mind is alert and chronic illness is slowly but surely eating away at that person's life, I believe personally that a lot of behaviour is born of fear, the fear of the unknown.

And once again I found that correct staff training and adequate communication with staff you often change those behaviours by how we approach the people, which once again is born of fear. Fear of and this is not fear of the

unknown, this is fear in a confused mind that from day to day does not know where they are and sometimes who they are, you know and that is dreadful to feel confused like that.

Carin recognised the urgency, born out of fear, in her patients, when diagnosed with a chronic illness. She said:

...want dit is gewoonlik met hulle so by jou aankom wil hulle NOU weet wat om te eet, want hulle is bang iets gebeur met hulle. So hulle het daardie vrees en hulle selfs, jy weet as pasiënte bel om 'n konsultasie te maak will hulle dan al weet wat om te doen, hulle wil nie nog 'n week wag om die dieetkundige te sien nie...

Understanding the need to know why

Dr. P acknowledged the need for patients to find a reason for their illness. She said:

Ja, and they often link it to an event as well. And they sometimes punish themselves too; they will say it is because I had an abortion when I was nineteen, now I have Cancer of the breast. God is punishing me.

Experience taught her that empathy also means not to challenge the belief system of her patients as this is their strategy to gain meaning and control over their illness. She said:

Ja, you have to stick with that (view of the patient). You cannot say to him you are talking a lot of rubbish that if you pray to God your HIV is going to go away. I can't tell him that because he does not believe that, he believes that it will.

Understanding the loss

Sharon is sensitive to the loss, a chronically ill patient might experience as a result of the illness. She also commented on the loss experienced by the loved ones. She commented as follows:

Of losing the person they knew. I have come to believe when a relative of your dies from Alzheimer's disease he dies twice, he or she. The person you knew dies and then the physical person.

Yes and loss of choices, it is another facet of nursing that we do here that I try to discuss a lot to my staff. Give the people choice, the small choices that they have left because there is so little. You know, they have to eat breakfast at half past seven and each meal at whatever and they have to bath in the mornings and not at night because it suits the staff and that kind of thing. So if a patient says to me I don't want to go outside I try very hard to respect those wishes because they have so little choice left. There is dignity in being able to choose what you want and what you don't want.

Empathy seems to emerge from the participants' own life experiences as well as from the nature of chronic illness itself. It seems that the more severe the illness is, the more understanding it evokes from the professional. In the case of Sharon, where she is confronted daily with patients in the final stages of chronic illness she seems to have developed a deep and empathic understanding of the process of being seriously ill.

Personal Reflections

The Voice of the Researcher

The interviews with the professionals were different from what I anticipated. In especially the interview with Dr. P, I was touched by how personal it was and how open she was to give insight into herself as a person and not only into herself as a professional. Although the stories were contextualised within the professions that they represent, they became more the stories of the individuals behind the profession.

I could strongly identify with the story of Carin as I myself, as a dietitian know the constant conflict between the impact of the patient's need and the role dietitians are

supposed to fulfill. I also understood the impact of the professional becoming the scapegoat and the representation of the changes required to live with a chronic illness.

I found the story of Sharon emotionally overwhelming. To listen to her and to comprehend the suffering she had to deal with, everyday for the last eighteen years, was humbling. I also realised that what she was telling me was based on the lives of real people. She in a sense repeated what was found in the literature that I have consulted, but in her story, the fear and the loss associated with chronic illness became real.

The common theme in all these stories, and I think mine as well, is the professionals' need to help others. It seems that helping those who are vulnerable gives our lives purpose and meaning. We need our patients just as much as they need us.

I also realised, that in spite of the limitations in training the participants, through experience, professionally as well as personally, acquired the skills necessary to empathise and respond to their patients' needs. It also seems that no one is a saint. They found they did not get along with some patients and in some cases were abused by them. In other cases the patients' needs were overwhelming and they had to withdraw. From an ethical point of view it is important for professionals to realise their shortcomings and be open about them.

Conclusion

The themes identified from the stories of the professionals working with chronic illness may be summarised as follow:

- Roles

Sub themes that emerged from the abovementioned theme included: the role of the professional, the scapegoat, the friend, the expert and the rescuer.

- Needs

Sub themes that emerged from the abovementioned theme included: needs of the patients and the professionals. Further sub themes included the need for acknowledgement and the need for self-preservation.

- Boundaries and Blind spots
- Differentiation vs. Integration
- Making Meaning of Illness
- Recognising the Power – The God Complex

Sub themes that emerged from the abovementioned theme included: power through knowledge and power in helping.

- Empathy

Sub themes that emerged from the abovementioned theme included: empathy through lived experience and through knowing the nature of chronic illness. Further sub themes included: understanding the chronic nature, the fear, the need to know why and the loss.

It seems that the nature of chronic illness demands from the professionals the ability to be flexible in the roles they fulfill. Working with chronic illness seems to require more than mere professionalism; the professional at times becomes the friend, scapegoat, expert and sometimes the rescuer. The professional becomes a friend, as the nature of the illness is chronic and the patient may visit the professional frequently over the progression of the illness. The boundaries of the professional-patient relationship may blur as friendships are formed. The professional may become the scapegoat of the patient's anger and frustration with his or her illness. The patient may 'blame' the professional for his or her misfortune. The role of the expert is often forced upon the professional due to the expectations of patients. Professionals, with their expert knowledge through training and experience are supposed to be able to cure illnesses. Chronic illness seems to challenge

this expertise and professionals sometimes need to decline the expert role. The role of the rescuer seems to be a role that the professionals fulfill, not only in their profession, but also in other spheres of their lives.

All three participants view their work in helping people as rewarding and see this as their motivation for carrying on. The needs of the patients, on the other hand are sometimes met with the professionals' needs for self-preservation and acknowledgement. Strategies such as setting boundaries and acknowledging blind spots were used to protect themselves in their relationships with the patients who they perceive as abusing or taking advantage of them. All three participants used different strategies in an effort to self-preserve. Dr. Pat would write about her traumatic experiences. She also read and tried to do nice things for herself. Sharon, at times withdrew from her family, which was hard for them. She also over the years at times sought professional therapy to work through what she referred to as her 'issues'. Carin realised she had to slow down and see less patients, so that she felt less rushed and stressed.

In working with chronic illness, Dr. P and Sharon became aware of the power their positions hold. Both cautioned against the danger of abusing their power in their professions. Carin, on the other hand experienced in her profession times of 'powerlessness' as her 'expert' position is often challenged.

Participants seemed to acquire the skill to differentiate between the patient and the illness when it was important to do so and at other times to integrate the person with the illness, depending on the demands of the situation. Differentiation was required when the professional realised that the illness determined the patient's behaviour. Integration was necessary in order to view the patient in totality, as a physical, spiritual and emotional being.

All three participants showed empathy. Empathy seems to be a process born out of the professionals' own life experiences and hardships, as well as a deep knowledge of the nature of chronic illness. This deep understanding of the process and nature of chronic

illness was specifically evident in the story of Sharon, who worked for more than eighteen years with the severely, chronically ill.

Being witness to the suffering of others forced the professionals to ‘make meaning’ of suffering. To be able to be with their patients in their suffering, both Dr. P and Sharon went through a processes of make sense of human suffering. Carin on the other hand did not refer to this.

All three participants were trained in the traditional medical model and are still practising primarily in health care systems, dominated by this model. It seems that although they acknowledged the limitations of this model in chronic care, they utilised their professional and personal experiences, personalities and desire to be helpful to others in creating meaningful and humane experiences for their patients.

In the next chapter a comparative analysis between the relevant literature and the themes identified from the two participant groups will be discussed. An integration of the themes identified from the experiences of the patients and the professionals will also be provided.

CHAPTER 7

A HARMONY OF VOICES

The Voices of the Patients, Professionals and the Literature

It is the stretched soul that makes music, and souls are stretched by the pull of opposites – opposite bents, tastes, yearnings, loyalties. Where there is no polarity – where energies flow smoothly in one direction – there will be much doing but no music.

Eric Hoffer, *Between the Devil and the Dragon*, 2: Introduction

Introduction

In this chapter the themes that emerged from the stories of the patients and the professionals will be discussed in relation to the relevant literature. This is not an attempt to substantiate the findings of this study, but to include many different voices on the same subject. First the themes from the patients' stories and the literature will be discussed, followed by the themes identified from the stories of the professionals and the relevant literature.

A Comparative Analysis between the Themes from the Patients' Stories and the Literature

Fear vs. Defiance

For the patients in this study, diagnosis of a chronic illness and having to live with it were associated with fear; not only the fear of life-long physical disability, but fear related to various other spheres of their life. However, the fear did not engulf them, as they fought back with defiance.

Pamela and Dick experienced *fear of the unknown* at the stage of diagnosis and/or when they first suspected that they might have a serious illness. Gloria, who did not experience fear at the time of diagnosis, did experience a *fear of the unknown* as her illness progressed. Pamela, when she started to contemplate the possibility of having Cancer, did not know what to expect. Dick was confronted with the unknown when he was experiencing the debilitating symptoms of Chronic Fatigue Syndrome without knowing what was wrong with him. Gloria, although denying fearing her illness at the time of diagnosis, did admit that the unpredictability of the progression of Diabetes was unsettling for her. Straus et al. (1984) highlighted the unpredictable or uncertain nature of chronic illness. Prognosis is often uncertain in chronic illness and therefore these uncertainties may bring considerable stress to the patient (Straus et al., 1984). This unpredictability gives rise to the feeling of not being in control and not knowing what to expect. The unpredictable nature of chronic illness and the accompanying feelings of being out of control evoked a *fear of the unknown* for all three participants. This fear did not only emerge at the first signs of chronic illness, but seemed to be a constant companion of chronic illness.

All three participants experienced, *fear*, not only for themselves, but for *their loved ones*. When Pamela was diagnosed with Breast Cancer and witnessed the pain it caused her husband, she felt it was more than she could bear. She also feared for the welfare of her young daughter, as she did not know what the journey with Cancer might entail, for herself and her family. Dick was also concerned that his illness was causing his wife distress. The exhaustion he experienced as a result of his illness impacted on his interaction with his wife as they were not able to share the same activities as before. Gloria was afraid that the etiology of Diabetes was genetic, and therefore her children might be at risk of becoming diabetic.

Being diagnosed with a chronic illness does not only have a life-changing impact on the sufferer, but also on his or her family. Wiley (cited in Gregg et al., 1989) suggested that the onset of a chronic illness might be viewed as an unscheduled crisis within the

structure of the family. From the patients' stories, it was evident that the illness impacted on their loved ones. It seems that the *fear for their loved ones* was born out of their own vulnerabilities. When being diagnosed with a chronic illness its sufferers may feel vulnerable, without protection; they therefore try and protect their loved ones. They may feel that even if they are unable to protect themselves; they can at least try to protect their loved ones (Strong, cited in Penn, 2001).

The patients concern for their loved ones therefore seems to mask their own fears and vulnerabilities. It could also be a coping strategy to focus on those you love rather than your struggle with your own mortality. To focus on others may give the sufferer some distance between him- or herself, and the threat of the illness.

The *fear of being labeled or judged* emerged as a theme from the patients' stories. Pamela did not allow others to see her pain as she was afraid of being labeled as 'depressed' which was in contrast to the persona she created as a positive and enthusiastic person. Dick, on the other hand was afraid of being labeled 'boring' as Chronic Fatigue Syndrome was not a visible illness or even medically recognised by some schools of thought. This fear of being labeled caused him to be silent about his illness. Gloria also felt that people would have preconceived ideas about her as a person if they knew she was a diabetic. Out of fear of being labeled, she therefore also resorted to silence. This is a silence she still maintains even ten years after diagnosis.

Strong (cited in Penn, 2001) refers to the social dilemma of illness; a person who has an illness may be viewed as socially defective. Such a person may be considered as morally defective, because, as a result of the illness, something must be wrong with the person. He or she may not be considered 'whole' anymore. Negative metaphors in the language of illness, such as "dependence, poor genes, repressed personalities, weak constitutions, et cetera" seem to underlie this social dilemma of illness (Penn, 2001, p. 39). The social dilemma and the negative metaphors of illness may elicit this *fear* from sufferers of illness *of being labeled or judged*. This seems to result in silence, which was evident in the stories of the patients.

A *fear of physical disability* emerged from the stories of Pamela and Gloria. Pamela, diagnosed with a severe form of Breast Cancer, was afraid of dying. She also feared the physical side-effects of the treatment offered. Straus et al. (1984) in their description of the nature of chronic illness refers to chronic illness as multiple illnesses. Sometimes, in an effort to control the specific illness, the treatment offered may cause other symptoms or even other illnesses. In the case of Pamela the chemotherapy or radiation may have had physical effects such as nausea and hair loss. However, she fortunately did not receive chemotherapy and tolerated the radiation very therapy well. Gloria feared the possibility of the complications of Diabetes. Diabetes can truly be perceived as a multiple illness as various organs, such as the pancreas, kidneys, eyes and the heart may be affected by the illness, which made Gloria's fear real and justified. This fear of the progression of her illness also drove her to be very controlled in her management of her illness. She felt that if she controlled her Diabetes perfectly, she might protect herself from its complications. However, the progression of chronic illness, such as Diabetes is unpredictable and Gloria had no certainty that she would escape from multiple organ damage later in her life. Therefore she constantly has to live with the *fear of the possibility of physical disability* later in her life.

Fear, as experienced by the patients therefore seems to be informed by the nature of chronic illness. The nature of chronic illness is described as life-long, intrusive, multiple, unpredictable and uncertain. This *fear* that accompanies chronic illness was reflected in the stories of Pamela, Dick and Gloria.

However, the *fear* was met with *defiance*. The patients were defiant in refusing to allow this fear to control them or the illness to destroy them. They fought back.

All three participants were defiant in keeping their identity. Pamela, who protected her identity as positive, enthusiastic, friendly and in control, was defiant in not becoming a victim of the illness. Instead she became a rescuer of others. Although she was the one who might have needed comfort, she opted to give support and comfort to others. The

diagnosis of Chronic Fatigue Syndrome forced Dick to take life slower. Although he incorporated changes in his lifestyle, he defiantly refused to give up his identity as a driven, high-powered businessman. Gloria was defiant in keeping her identity as a ‘coper’ and did not allow her Diabetes to significantly impact on her life. She never incorporated the illness fully into her life, however treated it as an unfortunate irritation that came along. Although Diabetes demands great lifestyle changes, such as a strict diet and rigid insulin regime, Gloria was *defiant in maintaining her way of life*. She did not allow the illness to control her lifestyle, but rather made her own choices in what to eat and when to use her insulin.

The defiance as described in the patients’ stories does not seem to resemble the anger or possible denial as described in the work of Kubler-Ross (1969) on the emotional responses in coming to terms with a life-threatening illness. The defiance seems to be more a process of having choices in how to live one’s life in the midst of a life-changing event. To be able to choose how to maintain their identities and lifestyles helped the patients to find meaning in the adverse event of living with a chronic illness. The ability to choose (defiance in the context of the stories) seems to reflect the process of making meaning from the trauma of being diagnosed with a chronic illness. In exploring the meaning of life through suffering, Frankl (1984) also refers to freedom of choice. To be able to choose his or her response in traumatic and adverse circumstances will empower the sufferer. The patients’ *defiance* lay in their freedom to choose. Pamela chose not to be a victim, but to rescue others; Dick chose to continue with his work, this is who he was; Gloria chose to cope with Diabetes and did not allow the illness to impact adversely on her life.

Acceptance vs. Rejection

Acceptance of the illness was a theme that emerged from the stories of Dick and Gloria. Both made the necessary changes to their lifestyles, which their illnesses respectively demanded. Dick accepted that he had to slow down and treated the process in the same businesslike manner he used in managing his business. He identified the problem, the

goal and the steps necessary to reach his goal. Gloria incorporated the regime of control of Diabetes into her life with precision and dedication. In this she felt that she was in control of the illness and not vice versa. Gloria, although she had integrated Diabetes into her life on the level of managing it, however compartmentalised the illness by viewing it as a separate entity. She accepted what she needed to do, to control the illness, but never accepted it as a significant part of who she was.

Acceptance, according to the Kubler-Ross model, is the stage where sufferers had to come to terms with their losses and find new purpose and meaning in their new circumstances (Kubler-Ross, 1969). In the stage of acceptance, the sufferer expresses ownership of solutions and is focused on achieving benefits (Kubler-Ross, 1969). According to Lubinsky (1994) acceptance will usually come with time, information and experience. Lubinsky (1994, p. 7) viewed acceptance as “a process, and not an end in itself”.

From the stories Dick and Gloria relayed, it seems that they achieved *acceptance* through the process of *rejection*. In rejecting advice given by lay-people as well as professionals who claimed to have solutions to the management of their illnesses, they decided whose advice to accept and whose to reject. Being able to choose the treatment offered as opposed to being told what to do seemed to make acceptance easier. *Rejection* in the context of coping with adverse events such as an illness is often associated with dismissal, denial and anger (Lubinsky, 1994). The patient may dismiss or reject the professional’s advice by questioning its legitimacy. According to Lubinsky (1994) this process happens when the patient is still in denial or in disbelief regarding the diagnosis offered by the professional. However, the rejection as experienced by Dick and Gloria seemed to be more on the level of being able to execute their own choices. Having a choice, in other words their own voice in the management of their illnesses, gave them a sense of control.

In contrast to the experiences of Dick and Gloria, Pamela’s story highlighted a different perspective of *acceptance* and *rejection* of illness. In retrospect, Pamela felt that in

accepting the doctor's verdict of the severity of the Cancer, without questioning it or exploring other options, she, at the moment of acceptance, gave up hope and expected the worst. She still refers to that moment of blind acceptance of her fate as the most traumatic of her life. Lubinsky (1994) warns about acceptance that is achieved too early, as it may result in devastation and all loss of hope. Early *acceptance* may force the person to surrender all hope, leaving him or her without time to process their losses, which is needed to make meaning of their new circumstances. "They need time to say good-bye, to let go of one world and move on to another" (Lubinsky, 1994, p. 7). Pamela, although at that moment, felt total shock and disbelief, fought back in the process of coping with her Cancer. For her, *rejecting the illness* itself was a way of coping. It seems that coping with a life-threatening illness such as Cancer, requires the sufferer to reject it and treat it as the enemy. Cancer is an illness that needs to be beaten and destroyed in order for the sufferer to survive (Armstrong, 2001). This is in sharp contrast to the stories of Dick and Gloria, where Diabetes and Chronic Fatigue Syndrome had to be integrated into their lives for them to cope with it effectively. It seems that the severity and nature of the illness may dictate the coping strategy required to live with the respective illness. Pamela, Dick and Gloria respectively chose the strategy that fitted best with them as a person and was dictated by their specific illness. To control Chronic Fatigue Syndrome and Diabetes, Dick and Gloria had to integrate it as part of their lifestyle, whereas Pamela could not accept Cancer as part of her and rejected on all fronts.

Connection vs. Disconnection

All three participants referred to the important *connections* they had either with *family*, *friends*, *other sufferers* or *professionals* that formed a network of support to help them cope with their illnesses.

For Pamela her connections with her family, friends and other sufferers were a source of great support. It is within these *connections* and relationships that she maintained old identities, created new identities and gained a sense of control over her illness. Pamela's story also highlighted a strong *connection with her Creator*, whom she utilised as a

spiritual anchor. Her experience of making meaning of the Cancer was deeply rooted in her reconnection with her Creator and her religious beliefs. She believed that she was healed through her faith. Pamela's faith and strong *connection* with God in a sense became a doubled-edged sword. The connection with God and her faith in her own healing was a great source of support and hope. On the other hand, it prevented her from expressing her real feelings of depression, as she perceived this as a sign of weakness and not having faith in God. She was also very reluctant to comply with regular checkups with her oncologist, as this might be perceived as losing faith in her complete healing.

Dick's *connections* were with his wife, his colleagues and his doctor and psychologist. Dick's illness seemed to silence him and his sources of support and *connection* were limited to his close and intimate circle of family, colleagues, professionals and friends. Gloria's strongest *connection* and source of support was with her doctor. He seemed to be the only person with whom she could break her silence and discuss her fears about her illness openly.

The creation of *connections* within the family system, which the sufferer may perceive as cohesive, flexible and supportive will have a positive effect on the individual's coping with his or her illness (Goodman, 2001). Support outside the family may protect the sufferer from stressful life events, such as illness or help to enhance life regardless of the stressful event (Goodman, 2001). From the patients' stories it is evident that the *connections* they experienced formed a significant part of their coping strategies. This was most highlighted in Pamela's stories as she created networks of support from various sources; loved ones, other sufferers, spiritual *connections* and to a lesser extent, the professionals. Dick limited his *connections* to family members, close colleagues and the professionals, whereas Gloria found the support she needed from her doctor. It seems that the more severe and frightening the illness, as in the case of Pamela's Cancer, the more support needs to be utilised. Dick's and Gloria's illnesses were perceived as 'silent' or 'stigmatised' illnesses and therefore support was limited to their immediate circles of family and/or professionals. However, despite the networks of *connection* and support all three participants experienced *disconnection*.

Pamela at times felt that, despite all the support she received, she nonetheless had to deal with her illness herself. She experienced *disconnection* and isolation in *dealing with her illness alone*. This experience was echoed by Gloria's story, who realised early in her illness that ultimately she alone is responsible for the management of her illness. *Disconnection* was also experienced in the patients' relationships with the *professionals, other suffers and friends*.

Pamela experienced *disconnection* in her relationship with the doctors who were treating her. She did not experience them as rude, but rather as cold and lacking in empathy towards her as a person.

Woolf (2005) relates this *disconnection* in the patient-professional relationship, specifically in the context of chronic illness, to the pressures and technology of modern medicine. Time, or rather the lack of it, results in short interactions between the professional and the patient. In other words, the professional's knowledge of the patient as a person is limited based on "discrete episodes, fixed in time" (Woolf, 2005, p. 1). Another factor, according to Woolf (2005) that affects the patient-professional relationship may be the advances in the technology of modern medicine. Modernism and the power of science have created the expectations that every problem has a logical solution. Professionals are traditionally trained to believe in the power of knowledge and science. If the patient and the professional are confronted with a chronic illness with an uncertain course, and prognosis and no cure, the relationship is confounded. When both patient and professional are confronted with a problem that may have no solution there may be conflict. The professional may have trouble acknowledging his or her impotence in providing solutions and the patient may be unable to admit to him- or herself that there is no affirmative action available (Woolf, 2005). In the case of Pamela, where her illness was severe and life-threatening, the doctors might have withdrawn due to in their own inability to cure her, which she experienced as *disconnection*.

In particular, Dick and Gloria experienced *disconnection from other sufferers and friends*. Their illnesses seemed to silence them. Both Dick and Gloria rarely discussed their illnesses outside the protective circle of family and trusted professionals. Pamela, on the other hand did experience some disconnection from friends at times, but she mostly utilised her connections to her benefit.

This *disconnection* may be linked to the theme of fear *of being labeled or judged*. Strong (cited in Penn, 2001) described the social stigma of illness and as a result its sufferers resort to silence. After being diagnosed the sufferer is afraid that people may view him or her differently and therefore they opt for silence in an effort to maintain their old identities (Holtzman, 2005). In their silence, as in the stories of Dick and Gloria, they may experience *disconnection* from friends and other sufferers.

In Pamela's story, a theme of *disconnection from the illness* emerged. For her, the whole process from discovering the lump to having surgery and radiation therapy happened so fast that she at times experienced it as not being 'real'. She also recalled the feeling of disconnection, despite having a life-threatening illness, as there were no visible signs and she hardly experienced any symptoms. Today, three years into remission, she experiences feelings of disconnection from the illness; as if it had never happened to her. At first the researcher interpreted this *disconnection* as denial, thinking that Pamela never came to terms with her Cancer. However, through revisiting her story the researcher concludes that this disconnection was an essential part of Pamela's coping strategy.

Lubinsky (1994) reported that patients with life-threatening illnesses often experience disbelief. They do register the medical findings and concerns, but experience a dissonance (disconnection) between what they perceive and the implications of these findings. In this process of coming to terms with their illnesses, they are left with trying to "comprehend, something outside of normal experience, something that goes against their common sense and everything their heart wants to believe" (Lubinsky, 1994, p. 7). It seems that this feeling of being *disconnected from the illness* is part of the coping process.

This disconnection that Pamela experienced may also be explained by the severity of her illness. It seems that Cancer is an illness that needs to be fought on all fronts. To beat Cancer it must be regarded as the enemy and it is never allowed to become part of its sufferer, as this may result in defeat and possible death (Armstrong, 2001). In this context it made perfect sense for Pamela to feel *disconnected from her illness*.

Loss vs. Gain

The stories of the patients reflected a theme of loss. Not only did they experience loss or possible future of physical abilities, but also a sense of loss in various other areas of their lives. *Loss of physical abilities, control, dignity* and *identity* were experienced or feared. The patients did mourn their losses, but were not overwhelmed by them as they were able to acknowledge *gains* in other areas of their lives. *Gains included control over the illnesses* as well as *new meanings* from the illness experience.

Patients experienced a *loss or possible future loss of physical ability*. Although Pamela did not have a mastectomy, she did fear the loss of her breasts during initial surgery and still fears the possibility of this loss in the future. The fatigue that was brought on by Dick's illness resulted in his withdrawal from the activities he used to enjoy. Gloria was contemplating the possible loss of physical ability that the progression of Diabetes may cause in future. She was also aware of the possibility of a shortened lifespan due to the debilitating nature of her illness.

According to Holtzman (2005) the *loss* of one's health (physical ability) and all the ramifications of this *loss* may present in a grief process with similar emotions as described by Kubler-Ross in her model of stages of grief. Therefore the sense of *loss* may also be accompanied by feelings of denial and isolation, anger, bargaining, depression and acceptance (Kubler-Ross, 1969). The participants in this study did experience similar emotions, although not necessarily in the specific order found in the Kubler-Ross model. Holtzman (2005) commented that in the experience of chronic illness a linear emotional

progression pattern cannot be found as physical conditions in chronic illness may vary significantly. This seems to be reflected in the stories of the participants.

Both Pamela and Dick experienced a sense of *loss of control* at the time of discovering something might be wrong. This feeling of *loss of control* intensified for Pamela when she was actually diagnosed with Cancer. Dick on the other hand was quite relieved when he was actually diagnosed as it provided an explanation for the confusion that he was experiencing, physically and emotionally.

The theme of *loss of control* may be explored in the context of the nature of chronic illness. The uncertainty and unpredictability of chronic illness may result in its sufferer feeling out of control (Straus et al., 1984), which was the case for Pamela and Dick. When suddenly confronted with an illness, for which there is no cure, the sufferer may experience a stage of disruption and *loss of control* (Morse & Johnson, 1991). This *loss of control* may manifest in various areas of the sufferer's life; physically, socially and emotionally the sufferer is confronted with possible changes that he or she cannot predict (Holtzman, 2005). This would seem to apply for all three participants. However, Gloria denied any feelings of loss of control at any point during her illness.

A theme of *loss of dignity* emerged from Pamela's story. She expressed embarrassment and feelings of vulnerability during her radiation therapy. Straus et al. (1984) describe the nature of chronic illness as intrusive as the illness intrudes in many areas of the patient's life, physically, emotionally and socially. The 'intrusion' as described by Pamela's story does not only reflect the physical 'intrusion' of the illness, but also 'intrusions' from the treatment offered.

A theme of *loss of identity* emerged from the stories of Pamela and Dick. Both struggled with their identities when confronted with their illnesses. Pamela, when she experienced symptoms of depression, struggled to reconcile her feelings with whom she perceived herself to be. Her self-image was one of a positive and enthusiastic person, so when she was confronted with a deep depression, her identity was challenged. Dick, as he realised

that his illness demanded a different lifestyle, struggled to redefine himself as less active and less driven. Gloria on the other hand denied experiencing a *loss of identity*; she maintained her identity through her silence. By not telling anyone she is Diabetic, she avoided the possible social implications or challenges to her identity. In a sense she also experiences a possible *loss of identity*, but by keeping silent avoided dealing with it.

Loss of identity is a central theme in the experience of chronic illness. According to Fitzpatrick (2002) the challenge to the identity emerges from the threat to the physical self which may be experienced as a loss of the core sense of the self. An illness may confront a person with how much one's identity is tied up with the possible *loss* of ability (Fitzpatrick, 2002). Dick's loss of identity was strongly associated with the loss of physical disability. However, in the case of Pamela it seems that it was the emotional response to her illness that she found difficult to integrate with whom she perceived herself to be. According to Holtzman (2005) some patients who have no physical signs of illness may choose to try and keep their illnesses a secret in an effort to maintain their original identities which was the case with Gloria who chose to keep her identity intact through secrecy.

All three participants counteracted their *losses* with *gains*. They employed strategies to *gain control and mastery over* their illnesses. All three participants gained control through *comparing themselves with others* who they perceived as worse off than them. Pamela compared herself to other patients whom she felt were worse off than her. She mentioned a patient who was younger, whose prognosis was worse and was receiving more treatment than she did. Dick compared himself to another woman with the same illness, but who according to him is not coping with the lifestyle changes the illness demands. Gloria felt that if she had to have an illness, she would have chosen Diabetes. According to her, Diabetes is perfectly manageable and controllable in comparison to other chronic illnesses.

The process of comparing oneself to someone else, who you consider worse off, is defined by Taylor (1983) as self-enhancement. This was one of the strategies that

Pamela and Dick employed to cope with their illnesses. Self-enhancement refers to the person's efforts to enhance him- or herself and restore self-esteem. In the context of chronic illness, self-enhancement helps to increase and boost the sufferer's self-esteem in an effort to cope with the demands of the illness. However, Gloria did not compare herself to someone else, but compared the nature of her illness with other illnesses. Nonetheless Taylor's explanation does still seem to apply to Gloria. The participants employed this strategy of self-enhancement in their own unique way, which served to increase their self-esteem.

All three participants *gained mastery and control through knowledge*. They sought knowledge from various sources, such as books, articles, professional advice and support groups to gain insight into their respective illnesses. Pamela read extensively on Breast Cancer and joined support groups in her quest to understand her illness better. Dick also read about his illness and kept on searching until he found an article on Chronic Fatigue Syndrome that he could identify with. Gloria gained her knowledge on Diabetes from reading, but mainly through her doctor who she regards as an expert in the field of Diabetes.

Knowledge from a social constructionist perspective constitutes power (Doan, 1997). Social institutions, such as the medical fraternity, hold power through their privileged knowledge (Doan, 1997). Therefore, the patient, in acquiring knowledge on his or her illness and treatment may *gain control* through the power in having that *knowledge*. The knowledge gained may empower the patient to make informed choices about treatment options and how to continue his or her life with a chronic illness. Being able to choose one's own destiny may create a sense of control. The patient is thus no longer a 'victim' of the illness or the health care system, but an active participant in his or her treatment. The stories of the participants reflected the role of knowledge in their quest to feel in control of their illnesses. The knowledge gained, empowered them to make their choices in how to live with their illnesses.

The social constructionist perspective informed this study. From this perspective, knowledge is regarded as power and how power is constructed within the relationship between the patient and the professional is considered as important in the context of this study. The question raised was: Who may claim the 'expert' position in this relationship; the patient or the professional? Both Pamela and Dick did not question the 'expert' position of their doctors as they both accepted their doctors' advice without questioning it. Dick however did reject some advice from other professionals, such as the dietitian he consulted. Gloria challenged the customary powerful position of the doctors; instead she formed a more collaborative relationship with a specific doctor who allowed her to be the 'expert' in the management of her illness. She used the stance of being the '*expert*' in the management of her illness as *a strategy to gain control*.

In a further strategy to *gain control*, the participants explored the reasons why they got ill in the first place. It seems that if they knew 'why', they felt their world was more predictable and believed they were more in control and thus less vulnerable. If they could identify the origin of their illnesses they could act on it and prevent it from becoming worse. In finding the cause they would be able to protect themselves against future onslaughts. Pamela believed that her Cancer stemmed from issues in her past that she did not deal with effectively. She was able to act on this by seeking therapy to resolve these issues. By actively dealing with what she perceived to be the reason for her Cancer, she felt that she could protect herself against further onslaughts. Dick thought his illness originated from his active lifestyle and his driven personality. If he was able to slow down and pace himself, he could protect himself from the debilitating effects of the illness. Gloria felt that if she only knew where the Diabetes was coming from she would feel more in control of her illness.

According to Taylor (1983), exploring the cause of illness is part of the process of making meaning out of the illness experience. In her study with Cancer patients the majority of her patients attributed their illness to some kind of theory, to general stress or to a particular stress. By understanding the cause it seems that they may find the significance of the illness in their lives and what it symbolises in their life. In this study,

the Cancer for Pamela symbolised her unresolved issues and for Dick his Chronic Fatigue Syndrome symbolised his hectic lifestyle and driven personality. Gloria was not sure what the Diabetes symbolised as she treated it as an uncomfortable irritation in her life, with no real impact, although, knowing 'why' would have given her the ultimate control she wished for.

The stories reflected the participants' ability to *gain meaning* from their illness experience. Meaning was gained either with the creation of new identities or insights from their lives. Pamela created meaning through creating a new identity. In the midst of her illness she felt like a 'victim' of Cancer, but as this identity did not fit with whom she perceived herself to be, she reached out to other sufferers and became a 'rescuer'. Dick was able to reframe his illness from having a debilitating effect on his life to a meaningful experience that gave him the opportunity to slow down and enjoy life more. Gloria felt that Diabetes, due to a possible shortened lifespan, highlighted life for her and helped her to maintain a positive attitude towards it.

Charmaz (1987) viewed identities as influencing and shaping the evolving self. The individual may base the personal identity on socially defined images of the self. Identity can be seen as a continuous process, as it may shift or change as a person reflects on images and identifications that the self and others confer upon him or her. The event of a chronic illness may shift these identities. Pamela felt that the Cancer challenged her identity. According to Charmaz (1987) some sufferers may aim to restore their old identities or, like in the case of Pamela, create new 'super' identities. Charmaz (1987) refers to this process of gaining a new 'better' identity as achieving a 'supernormal identity'. The 'supernormal identity' is achieved if the sufferer maintains or achieves a level of success and social acclamation in the competitive world. The person with the illness over-achieves in comparison to 'normal' people despite the limitations of his or her illness. As an example from this study, Pamela through her illness experience, became a source of support to her friends and other sufferers and as a result gained a new, 'super' identity.

Gaining new meanings from the illness experience may result in a new and positive attitude towards life (Taylor, 1983). Finding new purpose and meaning in their new circumstances may also indicate that the sufferers came to terms with their losses and reached some form of acceptance. However, chronic illness is unpredictable and uncertain in its progression; therefore no final stage of ‘acceptance’ may be reached as over time the ramifications of the illness may force the sufferers to continuously adapt to their changing circumstances (Holtzman, 2005).

The stories of the participants reflected the *new insights* and *meanings* that they have *gained* from their illness experience, although in the light of the nature of chronic illness this cannot be interpreted as a final stage of acceptance.

To conclude, the stories of the patients’ reflected their vulnerabilities in coping with a chronic illness, but were also stories of determination, courage and strength. These stories celebrated life, despite chronic illness.

In the next section the themes that emerged from the professionals’ stories will be discussed in context with the relevant literature.

A Comparative Analysis between the Themes from the Professionals’ Stories and the Literature

Roles

Chronic illness seems to demand that professionals need to fulfill different *roles*. From the stories of the professionals it seems they fulfilled these different *roles* assigned to them by their patients and the nature of chronic illness. They defined their *professional role*, in terms of by their respective professions; Dr. P, the physician, Sharon, the nursing sister and Carin, the dietitian. They also fulfilled the *roles of the scapegoat, the friend, the expert and the rescuer*.

This ability to fulfill different *roles* and incorporate different identities, depending on the interaction with their patients, may be informed by the social constructionist view of identity. Identity, from this perspective is not a fixed and stable concept of the self, but is socially constructed within the relationships with others (Gergen, 2000). This means therefore, that identity may be an “ever-changing collective construction” (Artus, 2003, p. 138). The *role* of the healthcare professional is also socially constructed within the context of healthcare. The patient with the problem (illness) seeks the expert’s advice to relieve him or her of the problem. In chronic illness this ‘fixed’ relationship may continuously evolve and change as the nature of chronic illness may demand more from the relationship, than the traditional patient-professional *role*. Therefore, the professional’s identity may alternate between being *the professional, the scapegoat, the friend, the expert and the rescuer*.

Professionalism may be traced back to the early part of the 19th century. People objected to the European class system differentiating between people as either the aristocracy or the proletariat. Rather, they wanted a social order, where status is based on merit rather than wealth and property. The role of the professional was born within this social context (Bledstein, cited in Baum, 2001). Today, professionalism is associated with status, privileges as well as responsibilities (Bledstein, cited in Baum, 2001).

Dr. P defined her *professional role* primarily as the physician, caring for the physical needs of her patients, but she is also aware of their emotional and spiritual needs. Sharon, as the nurse defined her *professional role* as that of the long-term caregiver for medical patients. Carin defined the role of dietitian as an educator to help people to live a healthier lifestyle. In defining their respective *professional roles*, the participants accepted their status as a professional and their responsibilities towards their patients: Dr. P took responsibility for the physical needs of her patients, without ignoring the fact that they have emotional and spiritual needs as well. Sharon took responsibility for the long-term care of patients, which also entails taking care of their emotional needs. Carin took responsibly for educating and supporting her patients to attain a healthy lifestyle in the management of their illnesses.

A theme of being '*scapegoated*' emerged from the professionals' stories. Dr. P reflected how patients vented their anger and frustration with their illness on her. Sharon also reflected on the abuse she at times had to tolerate from patients. Carin, often felt blamed for the patients' illnesses and non-compliance with their treatment.

The diagnosis of a chronic and life-threatening illness is often met with anger and it is often the bearer of bad news who bears the brunt of the anger, as described in the experiences of the professionals in this study. Lubinsky (1994) argued that '*scapegoating*' the professional lies in the anger and frustration of the patient, especially in the context of chronic illness where no cure is offered. '*Scapegoating*' may become part of a process of dismissal. The patient no longer focuses on the "information *per se* but on the legitimacy of its purveyors" (Lubinsky, 1994, p. 10). Devaluing the competence of the professional provides a way to disregard recommendations (like in the case of Carin) as well as a rationale for disregarding the clinical relationship (Lubinsky, 1994). It is possible that the frustration of the patient is accompanied by the expectations created by the power of science (Woolf, 2005). In modern society we are taught that science may fix all possible problems. When a patient is confronted with a chronic illness, which science can merely manage and not cure, this frustration may lead to feelings of betrayal by the health care system. It is the professional, who bears the brunt of this anger and disappointment.

All three professionals formed *friendships* with some of their patients. Dr. P experienced the loss of a friend when she was on vacation and one of her long-term patients died. She described a mutual fondness in the relationship between her and the patient. Sharon also described feelings of loss when long-term patients died. Over the years she built valuable friendships with her patients and their families. Carin, too formed relationships with her patients beyond what was required professionally.

In chronic illness the boundaries in the patient-professional relationship seem to blur. This may be as a result of relationships that form over long periods, often due to the

nature of chronic illness. The patient may visit the professional frequently over prolonged periods and the boundary between patient and professional may become blurred as they start connecting on a different level, sharing personal experiences in conversation.

The patient-professional relationship is based on trust, confidence and responsibilities towards each other (Davis, 2004). Boundaries within this relationship are flexible and not fixed, although traditionally it is believed that professionals should keep their distance (Davis, 2004). However, even Hippocrates in his teachings to students highlighted the importance of knowing your patient (Davis, 2004). According to Kee (1995) the majority of patients visiting professionals do not only seek technological answers, but also seek some kind of relationship, such as a *friendship*.

Needleman (cited in Kee, 1995) described that the centre of healthcare is within the relationships formed.

What was clear was that with all the technology in the world, medicine remained almost entirely a matter of human relationships. With all the science in the world, the actual treatment of illness remained a matter of human relationships, without which science was not only powerless but even destructive (Needleman, cited in Kee, 1995, p. 6).

The professionals in this study seem to value the power of healing in the quality of the relationships they formed with their patients.

The *role of the expert* emerged as a theme from the professionals' stories. Traditionally, it is believed that the professional, due to training and expertise is the expert in the patient-professional relationship. Although the professionals did claim the *expert role*, when appropriate, it seems to be challenged in the context of chronic illness. Dr. P acknowledged that specifically in chronic illness, the illness and sometimes the choices

of the patient, determine the outcome of the illness progression, regardless of her input. Carin as a dietitian, felt threatened in her role as a nutrition expert. She experienced that her expertise was often challenged by patients, their families and other professionals. The *role of the expert* did not appear to be an issue for Sharon, as she defined her role as that of a caregiver, rather than an expert in her field.

The challenge to the professionals' expertise may be informed by the nature of chronic illness. Decades ago, when acute illness was the focus of attention, the *expert role* of the professional was unchallenged (Baum, 2001). However, the ever increasing population of people suffering from chronic illness is challenging the *expert role* of the professional (Baum, 2001). Professionals, as they are unable to cure chronic illness, have to settle for managing it, in a collaborative relationship with the patient. The once powerful and *expert* status of the professional within the patient-professional relationship is challenged in the context of chronic illness. Thus, the professional is no more the 'fixer' of illness, but in partnership with the patient attempting together to manage chronic illness.

Another factor that may challenge the *expert role* of the professional in society today is the accessibility of knowledge. The professional is no longer the gatekeeper of information on illness and health, as information is more accessible to lay-people. Thus, the professional deals with an informed patient, who can make his or her own choices regarding treatment. This was specifically the case with Carin, as she felt more and more challenged in her role as the nutrition expert.

All three professionals fulfilled the *role of the rescuer* in their relationships with their patients. From their stories it was evident that this role did not necessarily evolve from their professional role, but was in fact an extension of roles they fulfilled since childhood or in other spheres of their lives. Dr. P felt that she was her mother's rescuer since childhood as her father was an alcoholic. Sharon felt that in her family system she played the role of the rescuer in resolving conflicts between her siblings. Carin, too felt that in relationships she is always the one trying to resolve conflict in an attempt to keep others happy.

The professionals seem to have claimed the *role of the rescuer* as it gave meaning to their life and work. To be a healer or to make a difference in someone else's life seems not only to be a professional orientation, but seems to be an extension of who they are as humans. Van Yperen (1996) refers to this orientation of helping others on the basis of genuine concern for their well-being, as communal orientation. He hypothesised that those healthcare professionals high in communal orientation may be less likely to suffer from burnout or compassion fatigue. Burnout and compassion fatigue refer to the emotional trauma that professionals may experience in treating their patients. They may suffer from emotional exhaustion, depersonalisation and feelings of reduced personal accomplishment (Truchot & Deregard, 2001). The professionals did experience emotional trauma within their working context, but seemed to be buffered against it overwhelming them. Despite their trauma they wanted to continue their work and experienced their work as rewarding and meaningful. Their genuine desire to be helpful, which is a reflection of who they are as humans, seemed to have buffered them against the emotional onslaught of working in the context of chronic illness.

From the stories of the professionals it seems that the nature of chronic illness constructed the roles they fulfilled in their relationships with their patients. Being a *friend* and a *rescuer* seemed to fit with their nature, whereas being the *scapegoat* seemed to be emotionally costly. They fulfilled the *role of the professional*, although boundaries were at times experienced as blurred, especially as time passed and the relationship became more familiar. Once again, the nature of chronic illness also seems to challenge their *role as the expert*.

Needs

In their interaction with chronically ill patients, the professionals seem to be very aware of the emotional *needs of their patients*. Dr. P, despite defining her professional role as primarily a caregiver to meet the physical needs of her patients, was very aware of their emotional and spiritual needs. She realised that she was not always able to take care of all

her patients' needs, but regarded being emotionally available to her patients as a vital component in treating them. It seems as if she realised that healing does not only lie primarily in the treatment of the symptoms, but also in the relationship between the patient and the doctor. Sharon, caring for seriously ill patients, was not only aware of the needs of her patients, but extended her care to their families. She realised their trauma of having a loved one with a chronic or debilitating illness and offered these families support and advice. Carin, who acknowledged the emotional needs of her patients, extended her narrowly defined role as a nutritional educator to being a support system for her patients in the process of accepting their illnesses. She helped them to understand their illnesses better and gave them the space to express their feelings regarding their diagnoses. In an often pressured healthcare system, she created a space where they could explore the implications of their illnesses.

Chronically ill patients require life-long attention as treatment includes taking drugs, sometimes having to limit their activities, experiencing relapses or developing complications due to their illnesses (Saslow, 2000). These factors leave patients of chronic illness emotionally drained and vulnerable. The health professional needs to understand the therapeutic power of treating their patients in a context of an intimate and trustworthy patient-professional relationship. According to Saslow (2000) such a relationship is only possible if the professional recognises the patient's emotional distress and encourages him or her to express such distress in words.

It seems that the professionals were able to create the space and opportunity for their patients to express their emotional vulnerabilities. In doing so, they recognised that healing (not necessarily curing) does not always lie within their technical expertise, but also within their humaneness.

However, in being sensitive to the emotional needs of their patients, they could become emotionally vulnerable themselves. According to Figley (2002) there is a cost to caring for those with chronic illness, with the realisation that these patients will never fully recover. The health professional needs to evaluate patients objectively and administer the

best possible treatment according to the best practice guidelines. However, the professional cannot avoid his or her compassion or empathy as these are the tools of healing. Compassion and empathy imply that the professional attempts to view the world from the perspective of the sufferer. Through this effort the professional could become emotionally vulnerable (Figley, 2002). Therefore, professionals also experience emotional needs as reflected in the stories told by the professionals in this study. Their emotional vulnerabilities also brought to light their *need for acknowledgement* and their *need for self-preservation*.

All three professionals needed some form of *acknowledgement* from their patients. They needed to know that their patients regard the patient-professional relationship as meaningful and helpful. Knowing that they are contributing to the well-being of their patients made their work worthwhile and meaningful. Dr. P experienced the positive feedback from her patients as rewarding and sometimes much needed. Sharon felt satisfied when she could recognise that her inputs made a difference to a patient's difficult day. Sharon regarded her workplace as a place of human suffering and felt that if her input relieved some of the suffering, it made it all worthwhile. When her patients acknowledged the difference her advice made to their lives, Carin experienced job satisfaction. Being able to make that difference in someone's life seemed to be the driving force behind the care the professionals offered to their patients. Experience taught them that at times they did fail and they were not able to help every patient that came through their doors, but having the knowledge that they did made a difference to some lives did buffer them against the emotional cost of caring.

Dr. P and Sharon developed strategies of *self-preservation* in an effort to safeguard themselves emotionally against the cost of caring for others. Dr. P expressed her feelings in writing when she experienced trauma in her workplace. She also tried to be kind to herself through engaging in relaxing activities such as reading. Sharon's workplace was a place of incredible human suffering as patients were at the end stages of their illnesses, with little quality of life left. She described times of feeling blunted or even detached in her interactions at work. For her, coping with pressures of her own, such as being a single

mother, she needed to withdraw emotionally at times. This seems to be a necessary defence mechanism if one is exposed to such intense human suffering.

Healing seems to lie within the ability of the professional to show compassion in his or her relationship with his or her patient. To recognise the patient's needs and to make a space available for the patient to express those needs will create a healing relationship. However, it is this ability to show compassion that makes the professional emotionally vulnerable and therefore the *needs* of the professional and not only the *needs* of the patient in chronic illness should be highlighted.

Boundaries and Blind spots

Although the professionals acknowledged the power of healing in the relationships with their patients, they became aware of the need to put *boundaries* in place when they experienced some relationships as abusive and stressful. Dr. P felt the impact of the interaction with some patients as abusive and manipulative. She described a feeling of "being devoured" by the needs of patients and in response found it necessary to put boundaries in place, even if it meant the termination of the relationship. Carin found that in her relationships with certain patients she took all the responsibility for their treatment upon herself. A *boundary* for her was to hand back this responsibility to the patient. Sharon, on the other hand admitted that setting up *boundaries* within her relationships with the patients was difficult. This difficulty may stem from the belief that good nurses, as caregivers, should care for their patients regardless of the response and actions of the patients. Erecting boundaries seemed to be difficult for all three professionals, as their natural instinct was to be caring and available to their patients. However, experience taught them that *boundaries* are necessary to establish the kind of relationship where healing could take place. For example, if Carin did not hand back the responsibility of the management of the illness to her patients, they would never have been able to gain control over it.

Boundaries viewed from a systemic perspective are the rules according to which a system operates, and these are defined by the relationship patterns within the system. These **boundaries** express the values of the system as well as the appropriate roles of behavior within the system (Becvar & Becvar, 1996). In addition, these **boundaries** are invisible and are inferred from the repeated patterns of behaviour of the system (Becvar & Becvar, 1996).

The **boundaries** within the patient-professional relationship are formed within the context of the health care system. The patient, with the problem seeks out the professional's expertise to fix or cure the problem. From previous discussions it is evident that the nature of chronic illness challenges this traditional perspective of health care, and therefore often the **boundaries** in the patient-professional relationship in chronic illness may become blurred. From previous discussions it may be concluded that blurred boundaries are often necessary in chronic care. Themes, such as the role of the friend and rescuer illustrated the need for more flexible **boundaries** in chronic illness. However, when the impact of the interaction between patient and professional becomes uncomfortable for the professional, **boundaries** need to be renewed or renegotiated.

Blind spots may be defined as a subject about which a person is ignorant or prejudiced, in other words one's vision or insight is obscured (Collins Reference English Dictionary, 1993). The professionals acknowledged the existence of **blind spots** in working with the chronically ill. Dr. P admitted that she preferred not having 'hypochondriacs' as her patients. She felt that they were manipulative, attention-seeking and time consuming and that she would rather spend time with patients whom she considered really ill. Sharon experienced 'personality clashes' with some patients. She experienced the treatment of patients she disliked on a personal level as professionally challenging, but attainable. Carin sometimes 'blamed' patients, who tried to shift the responsibility of their illness on to her, as her **blind spot**. Patients' who made her feel as if she had failed them were also difficult for her to deal with.

In the context of health care, working with people at times bring out uncomfortable feelings the professional may experience (Castro, 1989). If professionals suppress these feelings, it may become emotionally damaging to themselves or their patients (Castro, 1989). *Blind spots* may affect their ability to see or judge clearly and may ultimately affect the quality of care offered to their patients (Castro, 1989).

These emotional feelings and responses in the patient-professional relationship may be explained from a psychodynamic perspective, with the occurrence of transference or counter-transference (Castro, 1989). Transference refers to when a patient has an emotional response to the professional based on any similarities to a significant figure, like a parent in the patient's past. The patient draws or transfers these emotional responses into his or her relationship with the professional (Castro, 1989). Counter-transference occurs when the professional responds to these transferred emotional responses with an emotional reaction of his or her own. The professional's feelings and responses may get in the way of being able to see clearly what is happening in the relationship. This distorted relationship gets in the way of the healing process (Castro, 1989). It is within these distorted relationships that the professional experiences a patient as difficult, blaming and thus frustrating to treat.

Professionals, like their patients are humans with flaws and unresolved issues. *Blind spots*, which may be damaging to both patient and professional, should be acknowledged. The professionals in this study showed self-awareness in their ability to recognise and express their *blind spots*. If the professional is aware of these *blind spots* he or she can act ethically towards his or her patient. Dr. P openly discussed her negative opinion towards Chronic Fatigue Syndrome, leaving the patient the option to seek help from another professional. When the *blind spot* is a 'personality clash', as described by Sharon it may become more difficult to resolve. However, through self-awareness she was able to act professionally towards her patients.

Differentiation vs. Integration

According to the Collins English Dictionary ‘differentiation’ means to “serve to distinguish between” (Collins Reference English Dictionary, 1993. p. 134). From the stories of the professionals the ability to *differentiate* between the patient and the illness emerged as a theme. It sometimes became necessary for them to separate the illness from the patient, in order to maintain a healing relationship with the patient. This *differentiation* or separation of the illness from the patient seems in line with the traditional westernised (modernistic) perspective as practised within the medical model. The medical model focuses primarily on the pathology of illness and not on the person with the illness (Morse & Johnson, 1991). Bernstein and Korngold (cited in Hornung & Shrady, 2005) stated that in western societies when a person becomes ill, the illness is viewed not as part of the self, but as something that can be removed from an otherwise healthy individual. This ‘reductionist’ view of illness within the context of this study seems to be a contradiction when dealing with the chronically ill. Chronic illness is complex and requires a more holistic and integrated approach than what the traditional medical model offers (Baum, 2001). However, from the professionals’ stories it seemed that at times it was appropriate to *differentiate* between the illness and the patient. In other words they needed to ‘remove’ the illness from the individual and view it as a separate entity. Dr. P used *differentiation* to put her patient’s anger or hostility towards her in context. She realised that the anger was a manifestation of the process the patient was going through in dealing with his or her illness and actually had very little to do with her. Thus, through her ability to *differentiate* between the patient as a person and the illness it helped her to maintain a healing relationship with the patient. Sharon realised that the demanding and even abusive behaviour of some patients, were caused by their illnesses or their emotional response to their illnesses, especially in cases involving brain pathology. By *differentiating*, it became easier to nurse ‘difficult’ patients. Carin realised that often non-compliance to dietary advice did not imply a rejection of her advice, but was as a result of patients coming to terms with their illnesses. From this perspective the relationship between Carin and her patient stayed intact and they could work together

towards future compliance. Thus, at times separating the illness from the person is required, as illustrated in the stories of the professionals.

The professionals did however find the medical model, especially during their training, in the treatment of patients with chronic illness, as limiting. They pleaded for a more *integrated* approach, which views the patient as a physical, emotional, social and spiritual being. Dr. P felt that her training did equipped her to treat the physical symptoms of the illness, but did not prepare her for the needs of the person owning the illness. The medical model's prescription to stay objective in your relationships with your patients, was problematic for Sharon. As she was involved in the long-term care of patients, often stretching over years, she did become involved with them on a personal level. In this context of care it was impossible to only focus on the illness, ignoring the person owning the illness. Carin in reflecting on her training, felt that although there were attempts to incorporate psychology into her course, it was never effectively integrated with the subjects on nutrition. This led to a fragmented approach in dietetics with the focus only on nutrition education, ignoring the psychological processes a patient may go through during the process of making those prescribed and necessary lifestyle changes.

This disillusionment of the professionals with the medical model in this study as the only treatment option is shared by an ever increasing number of professionals working with chronic illness. Harris (2005) pleaded for the introduction of a more holistic and *integrative* approach in the care of the chronically ill. The holistic approach to health does not reject the medical model or conventional medicine, but promotes the view “pertaining to all aspects of human nature – physical, mental, emotional and spiritual” (Harris, 2005 p. 1). An *integrated* approach to care will involve addressing the person as a whole, and not only the area that is manifesting the symptoms. By creating a more integrated approach in chronic illness, the medical model may be supplemented with alternative models, such as the Health Belief Model and the Illness Constellation Model, as discussed in Chapter 2 of this study. Both these models were not developed as an alternative model in place of the medical model, but rather to help the professional

working in health care to develop an understanding of the patient's emotional response, as well as perceptions regarding his or her illness.

Although the professionals did experience their training as limited, especially in the context of chronic illness, they nonetheless through experience and the teachings of their patients developed skills to treat their patients holistically. They did acknowledge the person behind the illness.

Making Meaning of Illness

The professionals witnessed the pain and suffering of others. In order to do this type of work they needed to make meaning of the suffering they often witnessed. Dr. P was challenged with her own questions of 'why do people get ill and why do they have to suffer?' Confronted with these questions she had to *make meaning* of the suffering of others. She thought of suffering as part of life and not necessarily a punishment for some kind of sin. When Dr. P was confronted with questions from others as to the meaning of patients' suffering, she felt that it was not up to us to decide or judge whether critically ill patients' lives are meaningful. She did however believe that sometimes the purpose of the life of a patient who is experiencing great suffering is to teach his or her fellow human beings compassion and humility. Sharon went through a process of trying to *make meaning* of the suffering she witnessed over the years. She went through stages of anger and even at times considered the value of euthanasia. She, like Dr. P came to the conclusion that maybe the meaning of suffering of others is to teach us about human courage, humility and compassion. Carin, who as a dietitian was less exposed to the vulnerable moments in chronically ill patients lives did not refer to this struggle of *making meaning* from the suffering of others.

Health care professionals are witnesses of suffering due to their role as caregivers for the ill and the vulnerable in society. All of us as humans have devised or adopted ways of understanding how the universe works. We create patterns that ascribe order to our world and lives, so that we can understand it (Mohrmann, Healy & Childress, 2000). We use

these belief patterns to *make meaning* and sense of our world. Suffering has the power to break these patterns, and confound our sense of identity and shake our closely held belief systems about God, the goodness and meaning of our lives (Mohrman, Healy & Childress, 2000). Mohrman, Healy and Childress (2000) explain how the professional may experience being confronted with the suffering of others.

And sometimes we, the caregivers, experience a shattering of our own meaning and order because of the sheer magnitude, the relentless recurring intensity of the suffering we see in our work (Mohrman, Healy & Childress, 2000, p. 2).

The stories of Dr. P and Sharon resembled this struggle of being involved in the reoccurring intensity and the suffering of others and how to try and make some sense of it. Mohrman, Healy and Childress (2000) state that often professionals ignore the questions that arise from the suffering they witness, in a process of denial, to keep their belief systems maintained and unaffected. However, if the professional denies the spiritual effect of suffering of others on him or her, he or she will be incapable of being part of the healing process of his or her patients. Professionals, in taking responsibility for those who suffer will put themselves at risk of having their personal sense of order and meaning shattered (Mohrman, Healy & Childress, 2000). It seems that both Dr. P and Sharon took that risk daily in their work with the chronically ill. It also seems that coming to the point of *making meaning* and finding peace is a continuous and drawn-out process too. Both Dr. P and Sharon seem to have struggled for years to reach the point of *making meaning* of the suffering of others.

Recognising the Power – The God Complex

Health professionals, especially doctors, are often accused of having a ‘God Complex’, meaning that they have power over life and death. Their decisions and actions may have huge implications for the lives of their patients. Both Dr. P and Sharon recognised the *power* they might hold in their relationships with chronically ill patients. *Power* may

come from the intimate details that the patient shares with his or her doctor. Dr. P became aware of her power in potentially destroying a whole family if she shared with a patient's wife how he contracted the HIV-virus. Instead, she lied by telling a story that made the man a hero in his wife's eyes. She did this because she realised that if the wife knew the truth the man would have certainly died alone, without the support of his family. Sharon, whose patients depended on her for all their physical needs, realised how powerful you can become if people are so dependent on you. Sharon felt that by letting a patient wait for his or her food or painkillers may constitute an abuse of *power*. The vulnerabilities of patients place enormous power in the hands of those who are supposed to help. Carin was the only professional who experienced a loss of *power*. This is possibly due to the fact that nutritional knowledge is available and accessible to lay-people through various forms of the media. She experienced this as a challenge to her role as the expert.

The patient-professional relationship as defined in westernised healthcare seems to be an unequal relationship, with the professional in the position of *power*. This *power* may be assigned to him or her by society and the patients themselves. Giorgianni (1998) describes this *power* given to the physician (professional) as follows:

We have given physicians extraordinary privileges and responsibilities for ordinary and special events in human life: they are usually the first to touch a newborn child and they are often the last to hold the hand of a dying person. They are given access to our most intimate secrets and our most primal fears, allowed to touch our naked bodies, and given permission to open our bodies and cut into our organs (Giorgianni, 1998, p. 6).

It seems that both Dr. P and Sharon realised this *power* in the nature of their work. They reacted with humility, knowing that it is a privilege and a huge responsibility to be allowed into the most vulnerable moments of a person's life.

The knowledge of the professional may also constitute *power*. The patient's life may depend on the expertise and knowledge of the professional. However, the professional's role as the only gatekeeper of knowledge is being challenged. "The media has revolutionised the relationship between doctors and patients" (Stuttaford, 2005, p.1) as health journalism exploded in the last few decades. Therefore, the relationship between the patient and the professional may become more equal as 'expert' patients are created through the accessibility of knowledge. Carin experienced her expertise being challenged and she needed to renegotiate her position in her relationship with her patients. Patients in society today, may not necessarily only seek knowledge, but are seeking a more equal relationship built on mutual trust, "reflecting a balance between scientific expertise and human compassion" (Giorgianni, 1998, p. 6).

Empathy

A central theme in the professionals' stories was their ability to show *empathy* for their patients. According to Giorgianni (1998) patients seek a professional with a genuinely caring attitude with an interest in nurturing conversations that communicate *empathy*, just as much as his or her clinical expertise.

Rogers (cited in Gladding, 2000, p. 130) describes *empathy* as the professionals ability to "enter the client's phenomenal world, to experience the client's world as it were your own without ever losing the 'as if' quality". Therefore, this means mastering the ability to enter into another person's world and still knowing you can return to your own. *Empathy* requires the skills of perception and communication. *Empathy* will however expose the professional to the emotional cost of caring (Figley, 2002). This seems to be the paradox of the professionals; without empathy and compassion, they can only rely on their technical skill and lose the opportunity to truly heal, but in having a truly healing relationship with their patients they will risk their own emotional well-being.

The professionals did take this risk and it seems that *empathy* emerged from their own life *experiences*. Dr. P felt that her own life experiences moulded her to understand the

world of the chronically ill patient. She was diagnosed with Nephrotic Syndrome at the age of ten and had to use chronic medication until her early twenties. The medication, which caused water retention resulting in weight gain, changed her appearance and she experienced a loss of identity. She also reflected on a near death experience during a time when she was critically ill. She regards this as a life-changing experience as it changed her perceptions of death and dying. Having experienced this, she felt she could openly discuss with patients their fear of dying. Dr. P was exposed to trauma throughout her life; her brother-in-law was murdered, she was attacked in her home and she worked with sexually abused children for years. It seems that these experiences shaped her in a way that she was now able to show *empathy* and compassion towards her patients. Sharon felt that her hardships as a single mother made her more sensitive to the suffering of others. In raising her children as a single mother, she too experienced suffering, which made her more open to the suffering of her patients. Carin felt that living with her mother-in-law, who has a chronic illness, gave her a better understanding of what her patients were going through. She realised how difficult it can be for patients to follow strict lifestyle guidelines that she often prescribes, in order to manage their illnesses. It is these personal experiences and vulnerabilities that helped the professionals to show *empathy* and compassion towards their patients.

The professionals in this study gained insight in what it means to be chronically ill from their years of exposure to chronically ill patients. From their stories it was evident that this knowledge of the nature of chronic illness was experienced, not via textbook descriptions, but first hand from being involved with the suffering of their patients. All three understood the fear that accompanies chronic illness. Dr. P reflected on the uncertainty and anxiety that patients experience when diagnosed with Cancer. Sharon showed compassion for her patients who were slowly losing their mental functions and described the fear and the world of confusion the patient was going through. Carin reflected on the fear she recognised in patients when they were diagnosed with a chronic illness.

Empathy in combination with their clinical expertise became one of the tools of their trade in creating healing relationships with their patients. These professionals, through experience and exposure to the suffering of others realised the importance of being human in their respective professions.

In conclusion, the professionals' stories reflected similar themes to the stories of the patients. It reflected their vulnerabilities, strengths and determination as humans in their professional roles in the context of chronic illness. Although, not the sufferers of illness, themselves, they too experienced emotional trauma. They, similar to the patients, did not allow their vulnerabilities to overwhelm them, but showed determination to continue their work with the chronically ill. These were the stories of professionals caring for the chronically ill; it however became the stories of the persons behind the profession.

The voices of both patients as well as professionals were enriched by the voices from the literature.

In the next chapter, as the final conclusion, the strengths and limitations of this study will be discussed.

CHAPTER 8

CONCLUSION

*Nothing arrives on paper as it started, and so much arrived
that never started at all.*

Elizabeth Bowen

The Death of the Heart; 'The World'

Introduction

In this chapter the study will be evaluated and its strengths and limitations highlighted. A summary of the themes identified from the patients' and the professionals' stories will be provided, followed by an integration of the themes of both the patients and the professionals. The researcher will conclude with suggestions for clinical practice, specifically focusing on the patient-professional relationship in chronic illness, as well as suggestions for further research.

Evaluating the Study

This study aimed to explore the experience of chronic illness from the different perspectives of both the patient and the professional. The study aimed to give 'voice' to the six participants and their experience of chronic illness. Each participant was given the opportunity to tell his or her story within the context of chronic illness. The hope was that through telling their stories, chronic illness, would be described in all its complexity. A further aim was that new meanings and insights might evolve for the participants.

Themes from each story were identified and discussed by the researcher. This was then followed by a comparative analysis between the themes and the literature. The researcher however believes that the themes identified in this study, were rich and unique and may add to the existing body of literature in creating a deeper understanding of the complexity of the experience of chronic illness. This was especially so with the themes identified from the experience of the professional in chronic illness. Existing literature seems to be

lacking in descriptions of the emotional world of the professional dealing with chronic illness. Hopefully this study may stimulate more research in exploring the emotional world of the professional.

The following themes were identified from the stories of the patients.

- *Fear vs. Defiance*
- *Acceptance vs. Rejection*
- *Connection vs. Disconnection*
- *Loss vs. Gain*

The following themes were identified from the stories of the professionals.

- *Roles*
- *Needs*
- *Boundaries and Blind spots*
- *Differentiation vs. Integration*
- *Making Meaning of Illness*
- *Recognising the Power – The God Complex*
- *Empathy*

Although the abovementioned themes reflect the different perspectives of the patient and the professional, their experiences were connected through the nature of chronic illness. Therefore, it seems that these themes reflected both sides of the same coin. The patients were the sufferers of the chronic illness, and their struggle to come to terms with it, as well as how to incorporate it into their lives were told. The other side of the coin reveals the professionals' experience highlighting the frustration of treating incurable illnesses and the emotional trauma of being the witnesses of others' suffering.

An integration of the themes from the perspectives of both the patient and the professional will now be given. This illustrates the researcher's perspective on how the

different worlds of the patient and the professional are connected through the experience of chronic illness.

An Integration of the Worlds of the Patients and the Professionals

Central to the experiences of both groups was the nature of chronic illness. Chronic illness is described as unpredictable, intrusive, life-long and life-threatening. This nature of chronic illness seems to elicit a process of emotional responses from the patients and the professionals.

In this study the patients reacted to being diagnosed with *fear*. This *fear* engulfed various spheres of their life. They feared the unknown, feared for their loved ones, feared that they would be labeled or judged and they feared the physical disability that the illness may have brought. The patients however did not seem to be overwhelmed by this fear as they reacted in *defiance*. They seemed to be defiant in maintaining their previous identities and their way of life.

The professional who through *empathy* is sensitive and aware of these emotions of his or her patients, seems to respond by fulfilling different *roles*. Empathy seems to be a function of the professional's own personal life journey, as well as his or her experiences as witness to the suffering of others. The professional seems to respond by firstly claiming the professional role. This is primarily his or her function within the context of chronic illness.

In this study, the physician responded to the physical needs, the nursing sister primarily focused on chronic care and the dietitian fulfilled the role of nutrition educator. However, the nature of chronic illness and the patient's response demanded that the professionals fulfilled other roles as well. They became a friend, a scapegoat, an expert and a rescuer.

Underlying these roles again is the nature of chronic illness. Chronic illness progresses over time and the professional and the patient may at times have prolonged and frequent contact and friendships may develop.

Often, as a result of the *fear* a chronic illness elicits, the sufferer may respond in anger and frustration. This anger and frustration may stem from the fact that a chronic illness is incurable and the ramifications are life-long. The professional may become the scapegoat of this anger. It is here where empathy as well as the ability to *differentiate* between the person and the illness is required from the professional. The professional through a deeply developed understanding of chronic illness needs to realise where the anger is coming from and that it is not necessarily directed at him or her, but born mostly out of *fear*. However, the professional may experience the impact of this anger as abusive and may react by instituting firm *boundaries* within the patient-professional relationship. *Boundaries* may take various forms; the professional may request that the patient finds another professional to treat him or her or the professional may make the patient aware of the process. The patient may then feel *disconnected* within this relationship as he or she feels that his or her needs are not being met.

The role of the expert may also be influenced by the nature of chronic illness. Traditionally in medicine, the professional is in the 'expert' role due to the privileged knowledge acquired through training and expertise. In the context of chronic illness, the illness progression and outcome are unpredictable and therefore challenge the 'expert' role of the professional.

The role of the rescuer or helper within the patient-professional relationship seems to be the choice of the professional. The role of rescuer seems to be a role that the professionals fulfill in other spheres of their life too. To be able to help seems to make their work and life meaningful. The role of the rescuer links with the professional's *need for acknowledgement* that his or her input is actually contributing to the well-being of the patient.

The patient, on the other hand may *accept* or *reject* the patient-professional relationship or the expertise of the professional. Rejection may be at the level of rejecting the advice of the professional or rejecting the professional on a personal level. The patient may also reject the illness and then project this rejection onto the professional, who may be perceived as representing the illness.

Acceptance of the illness by the patient may be easier if there is acceptance of the professional and his or her advice. In this climate of *acceptance* mutual trust may develop and the patient and the professional may form a united front against the illness. This relationship will then become a source of *connection* for the patient.

It is within the patient-professional relationship that 'fit' seems to be important. If the professional is aware of his or her own *blind spots*, they should be communicated openly if appropriate, to give the patient the opportunity to seek a professional who would 'fit' his or her needs and with whom a connection is possible.

Loss seems to be central to the experience of chronic illness from the perspective of the patient. *Loss* was experienced in different spheres and forms. Firstly, chronic illness seems to be met with the possibility of loss of physical abilities. Even if the loss of a physical ability is not experienced at first, it is something the sufferer will be contemplating in the future. The reality of losing one's physical abilities seems to bring on a feeling of loss of identity. It is not only the physical threat that challenges identity, but the emotional responses to the illness, such as feelings of depression, that may also challenge perceived identities. Loss of dignity may also be experienced, as medical treatment may be experienced as intrusive and the patient may feel physically and emotionally exposed. The unpredictability of chronic illness seems to constitute a feeling of loss of control. These experiences of loss may leave the patient with feelings of vulnerability.

The professional, through *empathy* and his or her genuine desire to help, is aware of these feelings and experiences of patients. Although his or her *professional role*, as

defined by training within the medical model, is to focus on the illness, he or she *integrates* the illness with the person owning the illness. The professional becomes aware of the physical, emotional and spiritual *needs of his or her patients*. The professional may or may not respond to all levels of needs. It seems as if this response may at times fluctuate as a result of the professional's own emotional vulnerability. Sometimes, he or she is able to fulfill the roles and offer *connection* to meet most of the needs the patient is presenting. However, at other times, for his or her own well-being, a *need for self-preservation* seems to kick in. Self-preservation may lead to the setting up of *boundaries*, emotional withdrawal from the situation or the implementation of strategies of *self-preservation*. These may include the seeking of therapy, implementing ways of expressing or simply by reducing the frequency of contact with patients. These strategies employed by the professional may lead to the patient experiencing *disconnection*.

In the acknowledgement of *the needs of the patient* the professional may be aware of the *power* he or she holds within the patient-professional relationship. The professional has to reflect on his or her own motivations within the relationship and often needs to make moral decisions that may influence the patient's life. The professional needs to accept and react to the *power* placed in his or her hands with caution and humility.

There seems to be a relationship between the severity of the illness, *need for self-preservation*, *boundaries* and the degree of *disconnection* the patient is experiencing. In this study this relationship was illustrated by the story of the Breast Cancer sufferer, Pamela, who experienced the most *disconnection* from the health professionals. It may be hypothesised, that the severity of her illness magnified her needs and vulnerabilities, which might have made the professionals vulnerable as well. To be able to function within the professional role of saving a young woman's life they possibly set up *boundaries* in an effort for *self-preservation*. She, on the other hand, experienced their response as *disconnection*, which left her even more vulnerable.

Sufferers of chronic illness seem to respond to the *loss* with strategies of achieving *gains*. They seem to achieve *gains* through making meaning of their illness, through comparing

themselves with those worse off than themselves and creating new identities. They may also perceive the illness as a life-changing experience that brought new opportunities to the fore and avenues to explore.

The role of the professional within the context of these *gains* is to be supportive and non-judgmental. The professional needs to be open and accepting of the meaning the patient associates with his or her illness. This may sometimes be in conflict with the professional's own personal views. It is therefore also necessary for professionals, who are often the witnesses of suffering, to *make meaning* of their experiences. It is only through their own processes of working through the moral, ethical and hurtful issues, within the context of chronic illness, that they are able to be empathic to the processes of their patients.

The different perspectives of the patient and the professional seem to be connected by the nature of chronic illness. The incurability, unpredictability and intrusiveness of chronic illness seem to have informed the experiences of the patients and the professionals. This study seems to have highlighted and deepened the understanding of the patient-professional relationship in the context of chronic illness.

Strengths of this Study

This study explored the experience of chronic illness through the 'voices' of the patients and the professionals. Their different experiences were connected through the nature of chronic illness. To explore chronic illness from both these perspectives provided rich descriptions in the understanding of chronic illness. Research, specifically related to illness and medicine is usually described from a modernistic perspective. Healthcare professionals are traditionally trained from this perspective. However, in this study, their experiences were explored from a social constructionist perspective, which allowed for the possibility of multiple realities and unique individual experiences. This study, by exploring chronic illness, from a social constructionist perspective allowed for the possibility of integration between the worlds of science and human experiences. In the

treatment of chronic illness, science and technology needs to be balanced by the human experience. In this study, both the worlds of science and human experiences were connected or integrated. The professionals represented their modernist training and orientation in science and technology, whereas the patients represented the humane, everyday experiences of living with a chronic illness. Both these 'worlds' were connected through the experience of chronic illness, which was not explored as a scientific phenomenon, but as a human experience. In exploring chronic illness from this perspective, it allowed for both these 'worlds' to come together and highlighted the importance of both; living with chronic illness, as well as treating it.

The social constructionist nature of this study allowed for a co-constructed reality to emerge between the researcher and the participants during the interviews. Thus, the researcher was able to bring to the conversation her understanding and experiences of chronic illness. She reflected on this in the conversations, which may have led to new insights for the both the participants and the researcher.

By following a qualitative research approach, it was possible to inform the participants about the research aims and process. The researcher was also able to inform the participants about her own personal views and interests regarding the research subject. However, she did not allow her views to dominate the stories of the participants, as it was their 'voices' that needed to be heard. The participants were allowed to tell the story in their own way, as they were viewed as the experts on their unique experiences.

Reliability was achieved in this qualitative research study. Reliability in qualitative research essentially refers to the evaluation of the quality of the research (Golafshani, 2003). In qualitative research, quality will refer to how the study fulfilled its purpose of "generating understanding" (Golafshani, 2003, p. 598). Therefore, reliability in qualitative research may refer to the trustworthiness, credibility and dependability of the findings of the study.

The data that emerged from the personal accounts of the six participants can be regarded as trustworthy, credible and dependable. All three patients were diagnosed with a chronic illness and had been living with it for an extended period of time, and can therefore, for the purpose of this study, be regarded as reliable and dependable sources. The professionals, who were interviewed, had extensive experience, especially in the field of chronic illness. Their experiences, as related in their stories, can be regarded as reliable and dependable sources in generating an understanding of chronic illness.

According to Terre Blanche and Durrheim (1999, p. 64) dependability in qualitative research may be assured by the researcher giving “rich and detailed descriptions that show how certain actions and opinions are rooted in and develop out of contextual interaction.” In this study the researcher aimed at grounding her interpretations by linking them to excerpts from the original text and the context in which they occurred.

Validity was achieved in this study. Validity in qualitative research is not a single, fixed or universal concept, but “rather a contingent construct, inescapably grounded in the processes and intentions of particular methodologies and projects” (Winter, cited in Golafshani, 2003, p. 602). Thus, validity refers to the credibility of the study, evaluating the findings as believable and convincing (Terre Blanche & Durheim, 1999). The researcher feels triangulation was achieved by the use of the different perspectives of both the patient and the professional, as well as relevant literature in exploring the experience of chronic illness. Chronic illness in this study was thus explored from multiple data sources. The researcher also assured credibility through continuously describing and explaining how she arrived at her interpretations and conclusions.

Limitations of this Study

The interpretations of the participants’ stories, as mentioned previously, were influenced by the researcher’s world, referring to her values and viewpoints. In the process of engaging with the participants, the researcher would have reflected these views in the manner in which she commented, structured and interacted in the interviews. In other

words, the stories that emerged from these interviews were a co-construction between the worlds of the participants and the researcher. The researcher was also passionate about her topic of interest which was motivated by her own personal experiences, and was inevitably reflected in her conversations with the participants and the interpretations of their stories. Therefore, the researcher acknowledges that the findings of this study was coloured by the lens through which she looked at this particular time. Another researcher may have highlighted different themes and/or included other themes. The findings of this study can therefore not be regarded as an absolute 'truth' for all patients living with and professionals treating chronic illness. The findings of the study can also not be regarded as an absolute 'truth' for the participants, as the stories and interpretations were coloured by the values and views of the researcher. The findings of this study may be more accurately described as a co-construction of the stories of the participants, the researcher's views and values (her own story), and the literature consulted.

This study can be criticised if evaluated from a quantitative or empirical perspective as the findings of this study cannot necessarily be generalised to a larger populations. However, it is the researcher's view, that the rich and in-depth descriptions as presented in the study are useful in the understanding of the experience of chronic illness.

From a quantitative or empirical perspective, exploring chronic illness from so many different 'voices' may be criticised as so many variables were present in the study. These 'voices' included different illnesses at different stages of progression, different professionals dealing with different aspects of illness and participants representing different backgrounds, ages and genders. The researcher purposefully attempted to include as many perspectives into the study as could be accommodated within the scope of the study, to ensure a richer, more 'multi-voiced' description of the experience of chronic illness. From all these different 'voices,' common themes were elicited that might stimulate further research, specifically regarding the patient-professional relationship in the context of chronic illness.

A further limitation was the fact that personal information elicited during the interviews was often of a very personal nature, which raised important ethical questions (Moon, Dillon & Sprenkle, cited in Rapmund, 1996). The researcher, in recognising the sensitivity and vulnerability of the participants, conducted the interviews ensuring that the participants were informed beforehand of the purpose and the nature of the interview. During the interview the researcher used her clinical judgment in being sensitive and empathic to their responses. They were encouraged to indicate when they experienced any discomfort during the interview. To protect the anonymity of the participants pseudonyms were used and details were changed.

The interviews elicited an emotional response from most of the participants. The researcher did reflect on this at the end of the interviews and had contact with the participants after the initial interview, via telephone conversations or e-mail. Follow-up interviews to reflect on the identified themes, would have contributed to a richer understanding of the worlds of the participants; however the scope of the study did not allow for that.

Areas for Focus in Clinical Practice and Future Research

In Clinical Practice

For the researcher, this study highlighted the importance of the patient-professional relationship within the context of chronic illness. The emotional responses elicited by chronic illness seem to be traumatic for both. It is within the context of the patient-professional relationship that the professional and patient may form a united front against the onslaught of chronic illness. Both the patients and the professionals seem to be aware of and accept the incurability of chronic illness. It is however within the patient-professional relationship that healing (not curing) is possible. Health professionals, over the entire spectrum of clinical practice, including psychologists, physiotherapists and occupational therapists are confronted daily with chronic illness. Empowering both the patient and the professional in forming a truly healing relationship will not only make

chronic illness bearable, but will enrich both their lives. The following guidelines for the patient-professional relationship, as derived from the findings of this study, are provided.

Guidelines for the patient-professional relationship

- A collaborative relationship with mutual respect, between patient and professional is needed. Expertise may be shared by both parties. Whereas the professional acquired technical and academic knowledge, the patient gained insight in the illness through living with it daily. Using the expertise of both perspectives may lead to them becoming a formidable team to cope with the challenges of chronic illness.
- Roles and needs must be clearly defined. The professional may realise that he or she is not able to fulfill all the needs of the patient, and therefore needs to be a facilitator of other networks of support. Other networks of support may include other members of the multidisciplinary team, such as psychologists and social workers. It may also include other family members or support groups. The patient too, could be informed about his or her roles and what to expect from the professional. The patient needs to communicate his or her needs clearly. If he or she is not coping with the emotional impact of the illness, he or she needs to communicate this to the professional.
- The professional needs to be aware of his or her blind spots. If he or she does not feel comfortable in the relationship with the patient or with the illness the patient presents, he or she needs to give the patient the opportunity to seek other help.
- If the professional experiences the relationship as abusive, boundaries may be implemented. Boundaries may take the form of ending the relationship or making the patient aware of his or her abusive behavior. However if roles and expectations are clearly defined, the implementation of strict boundaries, might be minimised.

- It is the responsibility of the professional to take care of him- or herself in the context of working with chronic illness. Strategies for self-care and self-preservation may be seeking therapy, expressing oneself by writing, engaging in relaxing activities or limiting contact with patients.
- The professional needs to acknowledge the power his or her position holds. He or she should constantly reflect on his or her own motivation and treat the power vested in him or her with caution and humility.
- The patient needs to be aware of the acknowledgement the professional needs at times. If the patient communicates that the effort is recognised and regards the contributions as meaningful, the professional will experience his or her work as satisfying and be able to continue to fulfill the roles that the patient requires.
- Human suffering confronts both the sufferer and the witness. Therefore, both the patient and the professional need to process the meaning of suffering to be able to confront chronic illness together. The professional, if he or she ignores the moral and ethical dilemmas associated with human suffering, might become emotionally overwhelmed in situations of crisis. This may lead to an emotional withdrawal from a patient in need. The professional also needs to be sensitive to the meaning the patient attaches to his or her illness. The professional should try not to be judgmental towards the explanations or meanings their patients attached to their illnesses, even if the professional has a different perspective.

In Future Research

The aforementioned suggestions for clinical practice seem to hold opportunities for future research. Studies aiming at exploring the patient-professional relationship, within the context of chronic illness, may lead to equipping both the patient and the professional in

the management of chronic illness. Research in this area may also stimulate significant changes in the training of, especially, physicians.

This study highlighted the importance of patients' coping strategies that 'fit' with their specific illnesses. For example, Cancer elicited a very different response in Pamela in comparison with Gloria, who had Diabetes. The nature and severity of the illness seem to be factors associated with the coping strategy. Research in this area may provide more insight into the world of the sufferer of a specific illness. A conclusion that may be drawn from this study is to caution against acceptance of theories or models suggesting a 'desired response to illnesses'. As highlighted by the patients' stories, it seems that different responses at different stages of chronic illness emerged and that acceptance is not necessarily the ultimate goal. More research of a qualitative nature, describing the rich and individual response to chronic illness, may contribute significantly to the understanding of the experience of chronic illness.

In addition, the richness of the personal accounts in this study could stimulate further inquiry into some of the themes highlighted here. For the researcher further research into the experiences of the professionals is needed. It seems that research in this area is limited to quantitative measurable concepts such as burnout, but the everyday inner world of the professional is ignored in the literature. Research in this area, will yet again have a significant influence on how health care professionals are trained and equipped for the future.

The researcher hopes that this study will stimulate more qualitative inquiries into chronic illness, specifically in the multi-cultural South-African context. In her experience this seems to be an area that has mostly been ignored. In light of an ever increasing South-African population suffering from chronic illness, research in this area needs more attention.

Conclusion

This study explored the experience of chronic illness from the perspectives of both the patients and the professionals. The stories of the patients represented the suffering that accompanies the diagnosis of a chronic illness. This suffering was experienced in various spheres of their lives; emotional, physical, social and spiritual. However, their stories also highlighted the strength and determination that individuals are capable of despite the onslaught of a life changing event, such as the diagnosis of a chronic illness. The stories of the patients celebrated life, despite chronic illness.

The stories of the professionals represented the emotional trauma of being witness to the suffering of others. Chronic illness demanded much more from them, than defined by their professional role. Their stories showed that professionals were in the first place human. Their interactions with their patients stemmed from a genuine compassion and desire to help. However, there was a personal and emotional cost to caring for the chronically ill.

Future studies, focusing on the unique patient-professional relationship in the context of chronic illness, may change the way health professionals are trained and possibly as a consequence create more healing relationships in the management of chronic illness.

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APPENDIX (I): Consent form

Study Title: The Different Voices of Chronic illness.

Researcher: Linde Viviers

I hereby give my consent as a participant of the study, that the information or content of the interview by the researcher may be used as part of a dissertation to qualify for a MA (CLIN) in Psychology.

I am aware that the information I give will be published as part of a dissertation.

I am aware that ethical guidelines regards the confidentiality of the information will be followed.

I am aware that I at any time may resign as a participant of the study.

I am aware that my personal identity details will be kept confidential.

I am aware that as a participant I will be interviewed. This interview will be recorded.

.....
Participant

Date:

APPENDIX (II) Interviews with the Patients

Onderhoud met Pamela

L: As ek 'n kort opsomming moet maak om jou bekend te stel aan die lesers wat sal jy wil hê moet ek sê?

Wie is jy ?

PA: Wel, ek is Pamela. Ek is 17 jaar al reeds getroud. Ek het 'n dogtertjie van 12 jaar oud en dis basically dit van my.. van myself.

L: OK ... Wat doen jy?

PA: Ek is 'n ... ek is in die verkope in –sales en marketing...en ons werk met die voedselindustrie die top voedselmaatskappye die top 15 maatskappye en ons verkoop allerande seasonings vir die fast food industry, die snack industry, die poultry industry en alles so dis nogal 'n stressvolle pos, maar ek geniet die challenges en die adrenalien wat saam met dit gepaardgaan.

L: OK. So jy funksioneer goed op adrenalien?

PA : Absoluut ja, ek hou van challenges en ek sit vir myself baie hoë goals gewoonlik en ek sit myself onder baie druk om dan daai goals te bereik, jy weet. So ...

L: OK. As jy vir my as jy moet begin as jy jou storie moet vertel toe jy siek geword het .. kan ek sê siek? Is jy gemaklik met die term?

PA: Ja Nee Nee absoluut.

L: OK. Waar sal jy begin? Wat is jou eerste memory – ja waar het dit begin?

PA: Ek sal toe ons drie jaar terug dis nou drie jaar terug toe ons Desember by vakansie was en ek het costume aangehad op die strand gelê en my bors het gejeuk onder my toppie en toe ek krap voel ek 'n klein knoppie onderkant op my bors onderkant my 'costume' op my bors gedeelte maar omdat 'n mens nie regtig weet van Borskanker of in my familie weet ... bewus is daarvan nie ... het dit glad nie eers my brein binnegegaan nie.

L: Was jy enigsins bekommerd of...

PA: As ek eerlik is was daar dae, dat wel toe ek dit net gekry het daai vakansie het was ek bekommerd ek het nie presies geweet waarom nie, maar iets het my gepla ..jy weet maar ek is nie seker...

L: Dink jy jy het dit probeer ignoreer?

PA: Ja ek dink so.

L: Wat het jy gedink? – as jy moet teruggaan na dit toe.

PA: Wel, die eerste ding het ek dit ligtelik opgeneem – ek het dit nie regtig ernstig opgeneem maar daar was oomblikke wat ek alleen was wat dit my onsettend bekommer het .. so ek het daar buite gesit gaan eenkant sit en gaan huil en gewonder weet wat as dit erg ... maar ek het het nooit maar die Borskanker nooit in my gedagtes gekom ek het gevoel dat daar dalk iets verkeerd gaan wees ,maar ek het dit nie ‘gelink’ aan Borskanker per sy .. jy weet. Ek het onthou ek het daar gesit en bid en gesê Here help my net .. ek weet wat is besig om te gebeur nie..jy weet, maar dan die volgende oomblik dan skuif jy dit weer af.. jy weet .. asof ,asof daar nie regtig iets is wat fout is nie. Want, ek meen jy wil seker nie regtig erken vir jouself daar kan dalk iets fout wees nie. Ek meen ‘n mens probeer maar altyd die positief kant hou.

L: Het jy dit met enigeen gedeel daai tyd of was dit iets wat jy vir jouself gehou het?

PA: Ek .. ek het net vir my ouers en my skoonouers almal gesê ek het ‘n knop op my bors gekry. My ma het my bly aanmoedig gaan dokter toe.. gaan dokter toe, maar ek het soortvan dis waar ek dit gehou het. Ek het nie gesê hoe ek regtig voel daaroor nie.Ook nie vir my man nie so ek het dit alles net vir myself gehou, daai.

L: En toe?

PA: Toe het ek werk toe gegaan in Januarie en toe gaan ek dokter toe. Toe besluit ek laat ek maar net gaan by my GP gaan hoor, wat dink sy. En toe kyk sy na die knop en sê: “Weet jy wat dit lyk vir my na fibrositis. Het jy Borskanker in jou familie of Kankers?” Toe sê ek: Nee niks waarvan ek weet nie en ... toe sê sy maar jy is heeltemal te jonk vir Borskanker ... en sy sê “Ek voel glad nie bekommerd dat dit enigsins erg is nie, maar ek wil graag hê dat jy spesialis moet gaan sien.” En toe maak sy vir my ‘n afspraak ... die 28 ste Januarie het ek hom gaan sien en toe hy vir my wel hulle moet vinnig die knoppie maar net verwyder lyk vir hom ook maar net soos fibrositis want die knoppie het eintlik net basies onderkant die bors gesit meer aan die ribbes se kant so waar jou bra se strappies sit net onder daai yster riffie.

L: Die goed wat hulle vir jou gesê het het dit die angstigheid weggevat?

PA: Ja, ja

L: Want hulle dink dis OK?

PA: So ek het maar eintlik...

L: So hulle weet wat hulle doen .. so dis OK?

PA: Ja –'n vinnige operasie net om daai knoppie te verwyder hy is baie klein ... dis maar 0.7cm of wat ook al .. dis baie klein en hy het vir my gesê dis 'n vinnige operasie , so. Ek onthou nog, ek het die dag net by die werk afgevat vir die operasie- dit was 20 minute wat ek was basies in die operasiesaal was, uitgekome en ek het soveel energie daai dag gehad jy weet ek het huis toe gekom.. my man het my gebring ek het.. dit het goed gegaan met die operasie , ek het niks sleg gevoel nie, jy weet, waar hulle het nog voor die tyd gevra wil jy tot van daai goed hê wat jou vinniger laat wakker word. Ek het niks gevat nie, maar ek het vinniger wakker geword as enige van die ander mense. So dit het goed gegaan, jy weet ... hy het 'n mooi sny gdoen, jy kon amper sny nie regtig sien, jy weet, baie mooi gedoen. En ek is die volgende dag terug werk toe so ek het regtig goed gevoel – niks het my gepla nie. En ek dink dit was so twee dae later toe bel hulle my man – ek moet inkom. En...

L: Wat het jy toe gedink? Wat gaan dan deur 'n mens se kop?

PA: Toe hy my bel, ag toe ek by die huis kom toe sê hy vir my die dokter wil jou sien. Toe weet ek – daar is iets groot fout en ek was 'heavy' angstig gewees, maar ek het nie geweet wat om te verwag nie. Dis soos jy weet daar lê iets vir jou voor, maar jy weet nie presies wat nie jy weet....

L: Sal jy dit beskryf as geweldig onseker?

PA: Ja , ongelooflik, want jy weet nie wat vir jou voorlê nie jy weet daar is iets nou verkeerd, want die dokter vra nie .. wat ek probeer het.. ,maar toe die aand toe ons gaan lê toe sien ek my man ... die trane loop so oor .. toe weet ek .. toe voel ek, jis ek is nog so jonk .. as daar iets moet verkeerd gaan.. my kind is nog klein , sy is toe 6 jaar oud, ag nee, omtrent 9 jaar, jy weet. Al daai gedagtes begin nou in my kop posvat, jy weet. En jy begin deal met daai ...

L: En toe jy sien hy is ontsteld, wat het dit aan jou gedoen?

PA: Dit het my dit was ... ek dink van alles was dit al klaar vir my die ergste, op daai punt ... dis asof hy iets weet wat hy nie vir my wil sê nie, om my die pyn te spaar ... in dis al en hy het gesê moennie worry nie, jy weet. Die volgende oggend toe ek by die werk kom bel ek dadelik die dokter, nou wil ek dadelik weet wat is fout, maar sy sê vir my niks is fout nie, kom net in ...die 'receptionist' daar , toe voel ek weer oraaait, jy weet. Daar is seker niks regtig fout nie, dis maar seker iets anders,toe kalmeer ek weer,want dit was die Woensdag, die Donderdag bel ek al, so ek moes die hele dag... want Vrydag wou hy my eers sien. So daai dag, toe voel ek nou weer oraaait, toe dog ek nee,dis net my 'imagination', dis darem nou nie so erg nie, sy sê daar is nie iets nie, kom in die dokter sal self met jou praat

L: So dis asof mens wag vir buite mense om sort van vir jou te sê dis OK?

PA: Ja dis OK-jy soek laat iemand vir jou sê :”moennie worry nie alles gaan OK wees” En die Vrydag toe ons nou daar sit, ag toe is ek gespanne. My ma het vir my gesê, maak nie saak wat gebeur nie, hou net vas, 'so what', 'so what' as dit iets verkeerd is – jy gaan daardeur kom.

L: Het jy dit geglo?

PA: Toe ek die nuus kry, het ek dit glad nie geglo nie- ek dink dit is die mees traumatiese ding wat iemand mee kan deel, as iemand dood oor jou lewe spreek. Vir my , ek meen, Dr.B is 'n fantastiese dokter, maar hoe die nuus oorgekom het .. op daai oomblik het ek probeer vasgryp aan lewe en dit het vir my gevoel of ek sand gryp en ek kry dit nie in my hand vasgehou nie, jy weet of so...

L: Wat is die boodskap wat jy gekry het? Hoe het hy dit aan jou oorgedra?

PA: Wat hy vir my gesê het, hulle het die knoppie geanaliseer en dit is Borskanker-baie aggressief. Agterna het ek uitgevind alle Borskanker is aggressief in elke geval, maar op daai oomblik het ek dit nie geweet nie, so – vir my gesê dit baie aggressiewe Kanker en verduidelik die estrogen en al daai goeters, wat ek nie verstaan het nie, in elke geval, maar omdat die knop nie in binne,bo in my bors was, maar op die plek waar hy gewees het, het hy vir my gesê “Dis so naby aan jou ribbes, so ons is nie seker of die Kanker al reeds in jou bloed en in jou bene in versprei het nie en as dit dan in jou hart kom is dit verby.” So dit was vir my ongelooflike skok is daar – wat doen ek nou, is daar vir my ...weet ... en hy het vir my probeer sê daar is nie hoop nie, jy weet. En hy het vir my

dadelik gesê ons sal jou moet vat vir ‘n tweede operasie, jy sal moet gaan vir chemoterapie, radiation alles wat daar beskikbaar gaan jy deur dit gaan en hy het dadelik ‘n ander spesialis ook gebel, terwyl ons in sy kantoor sit en gesê “wat doen ons nou?”

L: Het dit jou meer angstig gemaak? Die feit dat hy nou nog iemand moet kry... dis nou regtig ernstig.

PA: Ek dink op daai het vir my bietjie meer comfort gegee asof hy kyk is daar iets ander wat hy vir my kan doen- hy dit nou vir my uigespreek, maar hy sê en dit het hy vir my gesê kom ek kyk wat kan ek help dis wat ek weet, maar kom ons kyk of daar nog iemand is wat kan help. So dit het my ‘n bietjie meer ...

L: Daar is opsies?

PA: Ja daar is nog opsies.

PA: En toe hy met daai spesialis praat toe sê hy omdat die Kanker daar gesit het, op daai spesifieke plek wat beveel daai spesialis aan toe sê hy net sny dieper uit op daai knop. En dat hulle my limfkliere en alles en dit was die Vrydag, die Dinsdag moes ek gaan vir my tweede operasie. So alles het toe nou vinnig gebeur ek moes, wel, ok om nie te vinnig te hardloop nie, dit was ongelooflik, ek het daar gesit en huil, vreeslik, jy weet, want die skok, soos ek vir jou sê dis om om te wonder, jinne hoe hou jy vas, is my man, my kind, soveel duisend dinge gaan deur jou kop. Is, ek is nog so jonk, daar is nog so baie dinge wat ek wou gedoen het, jy weet, hoe, wat van my kind, dis al, die meeste wat my vreeslik gepla het, jy weet. En ek onthou dat ek ma gebel toe ek uit in die kar geklim het, onmiddelik.

L: Jou ma gebel het

PA: Ja, eerste my ma...

L: Hoekom dink jy bel ‘n mens jou ma ?

PA: Ek dink omdat jou ma vir jou ‘n ... ‘n standvastige figuur, iemand wat vir jou deurdra wanneer dinge verkeerd gaan, as iets verkeerd loop weet jy jy kan jou ma vertrou, sy gaan vir jou dalk sê wat moet jy doen of vir jou raad gee of wat ook al. My ma was nog altyd so vir my as ek deur krissise gaan is sy altyd daar, jy weet of as ek sleg voel dan weet ek dan bel ek haar dan, dan bid sy dan sê sy gaan sing nou dan voel ek beter, jy weet. En op daai oomblik het sy dit net so erg gevat soos ek. Vooraf het sy gesê “come what may” – dit maak nie saak wat se nuus ons kry nie, maar dit was vir haar net

so 'n groot skok, want ons het nie verwag dis die, jy weet die nuus wat ons sou gekry het nie.

L: Hoe het geweet sy het dit half nie hanteer nie?

PA: Want wat sy gewoonlik, hoe sy gewoonlik teenoor my reageer ... so sy sal sê bid – kom ek bid gou vir jou... begin die Here loof en prys en sing en so aan...Maar sy het dadelik gehuil en net gesê... “Moennie worry nie, moennie worry nie”, maar ek kon hoor sy was baie ontsteld gewees. En toe begin ek, toe bel ek my werk. Want nou weet ek ek moet Kaap toe vlieg die Maandag, ons het dinge gereël, ek voel verantwoordelik vir dinge wat ek moet doen, jy weet. En toe bel ek, toe sê ek hulle moet a.s.b. al my trips kanselleer. En toe begin my baas my bel en mense het gehoor daarvan wat my bel en net moed inpraat.

L: Hoe het dit jou laat voel?

PA: Ek dink vir my, omdat ek met baie Christene werk en hulle my ken dit het my net gehelp dat ek nie in depressiewiteit onmiddelik ingesak het nie. Want ek meen 'n mens is so ek het vreeslik jammer vir myself gevoel, ek meen daar wou ek die wêreld notify toe sê: “Please look at me I a going through a terrible time” So almal wat ek ‘basically’ ek geken het, ek meen Ronel het ek onmiddelik gebel, jy weet en mense gebel.

L: So jy het mense gesoek?

PA: Ja,

L: Jy het nie blootgestel gevoel nie?

PA: Nee, ek het mense gesoek. Ek wil net hê mense moet vir my ..., ek weet nie, as ek nou daarna kyk, seker sê dis oraait, jy weet, of net weet hulle is daar...

L: Jy is nie alleen nie....

PA: Ek is nie alleen nie. Ek het my skoonma gebel en ek het vreeslik gehuil en sy het gesê: “O, ek wens ek kon nou daar gewees het om jou 'n drukkie te gee, maar ons bid vir jou.” En toe het die familie begin een agterna die ander een bel en so, maar ek was baie depressief gewees. Want ek weet nie hoe hanteer mens so... ek dink van, as ek weer terug kyk, was dit die ergste traumatiese oomblik, was daai dag. Niks anderse was vir my so erg soos om in die kantoor te sit en dit te deal nie, jy weet Ek dink die tweede operasie was ook traumaties gewees want toe moet ek nou weer gaan vir die tweede operasie, seweur die oggend daar wees. My ma en Pa het vroeg van Pretoria af gekom om my te

vat. My Pa het my gesalf en my gebid en my broer gebid, so dis 'n baie emosionele ding. En, en, jy weet my vriende, wat gekom het soontoe, toe 'n prayer group agterna gevorm het, terwyl ek deur die goed gaan en so aan, maar nie eers dit was vir my so erg soos daai oomblik toe ek in sy kantoor gesit het nie en dan vir my daai nuus gegee het nie.

L: As jy reflekteer, dink jy, jy kan jou lewe soort van sien tot op daai oomblik en van daai oomblik nooit weer heeltemal die selfde nie? Daai duidelike significant oomblik? Ek weet nie, ek vra vir jou ... Dink jy jy dink aan jousef as die tyd voor dit en die tyd na dit. Of nie regtig nie?

PA: Sjoë, eintlik, ja. In a way, dis moeilik om as ek nou vinnig daaraan dink, ek praat dan dink ek aan my lewe soos dit was sonder ... vir my partykeer is dit so moeilik om regtig te realiseer waar deur ek gegaan het. Want dis asof ek nie daardeur gegaan het nie.

L: ... omdat dit so erg was?

PA: Ja dit is en as ek nou terugkyk, dit is so baie trauma waarmee jy deal en partykeer moet ek stilsit en dink: "Sjoë maar ek is daardeur, jy weet. En ja dit is amper asof jy nie daardeur gegaan het nie. Dit is asof dit met iemand anders gebeur het, maar jy weet jy het daardeur gegaan, want ek meen jy het die merk op jou liggaam en goed om te bewys jy is daardeur.

L: Amper asof jy jousef moet herrinner?

PA: Ja, Ek is daardeur, jy weet. Ek dink een ding wat vir my wonderlik is wat die Here seker wat hoe 'n mens se lewe beplan word vooruit, sonder dat jy weet. Die Bybel sê: "Die mens wik, maar God beskik". My vriendin het 'n naweek weggereël vir ons en my dogtertjie was toe saam met hulle en dit was toe 'n partytjie. Ek bel haar toe die Saterdag en sê ek wil glad nie gaan nie. Ek wil vandag by die huis sit en ek wil vir myself baie jammer voel. Ek sê dit reguit. Dis hoe ek voel. En ek is nie eintlik 'n depressiewe ... maar ek dink dit was net so 'n groot iets om te deal jy weet nie hoe vorentoe nie jy weet nie wat lê vir jou voor ...dit voel amper of jy klaar jou tassie moet pak en gaan lê en wag vir die dood. En toe sê sy vir my "ek hoor wat jy sê en ek verstaan dit maar ek vra dat jy sal kom, jou kind is in elk geval hier so jy moet haar kom haal" en so aan. En daar kom ek en ek moes gaan, jy weet en die pad soontoe ek sal dit nooit vergeet hoe ek soontoe ry en mense, my tannie het my gebel, sy het vreeslik gebid, my ma se vriendin het gebid, jy weet en so aan. En toe ons daar aankom is daar 'n hele groep mense wat nie weet van my

omstandighede nie. En hulle fokus nie op my nie, hulle fokus op die partytjie en ek, en een vrou het nog gepraat oor Borskanker daar en ek dog by myself hierdie mense weet niks, maar hulle het nie aandag aan my geskenk nie. So, waar ek kon seker in depressiwiteit daar verval het, daai dag...

L: Het jy dit verkies, half dat hulle nie weet nie of was daar iets in jou wat wou sê...?

PA: Daar was iets in my wat hulle wou laat weet – ek gaan deur dit, maar ek het stilgebly.

L: Hoekom dink jy?

PA: Want, ek dink 'n mens wil nie loop, dis asof jy nie wil loop en 'bragg' seker... ek weet nie of die geselskap draai na jou kant toe nie, ek meen was ons daar om 'n kind se verjaarsdag te vier, dis vreemde mense wat ek nog nooit voorheen ontmoet het nie, hulle ken my glad nie, so dit sou onregverdig wees dat ek my, asof ek my saak hulle saak nou sou maak, jy weet – my las hulle las maak en ek wou nie dit doen nie.

En toe die hele dag het ons saam gekuier en alles en so aan en toe laat die aand toe kry ek vir die eerste keer 'n kans om met my vriendin te gesels – toe huil ek, jy weet, toe sê ek vir haar waardeur, hoe ek voel en so aan en, maar sy het dit so goed hanteer, ek meen sy het my nie, oor jammer gekry of vir my opgepiep of so nie – sy het my aanvaar asof daar niks met my verkeerd is nie. En ons het nog gaan swem die aand – jy weet ek is net die vorige paar dae nog 'n operasie gehad, ons het geswem, sy het 'n bal gebring, ons het gespeel en dit het my net uit daai ding heeltemal uitgetrek – daai depressiwiteit... En toe ek begin weer in normal weet, begin swem en saam met almal en saam met almal speel en daai tipe ding...

L: Amper soos jy lewe nog?

PA: Toe vergeet ek vir 'n oomblik...

L: JY IS NIE DOOD NIE?

PA: Ja, toe vergeet ek vir 'n oomblik van wat nou op hierdie stadium met my gebeur. Maar ek meen, jy voel nie siek nie, jy voel niks nie, dis net die dokter het 'n doodspraak oor jou lewe gegee, jy weet. Dieondag is ons kerk toe, ek het daaiondag toe onthou ek staan ek so, bid ek en sê: "Here, vandag gaan ek kerk toe nie om iets te ontvang nie, maar om vir U te sê Jy is Groot" En ons het 'n spesiale pastoor, dis net amazing as jy terug kyk oor jou lewe oor hoe alles gebeur, ek weet nie. En ons begin toe sing en ek besluit ek

gaan vannaand net die Here loof en prys. Forget about the rest en my vriendin, en die mense wat daai naweek saam met ons was sit ook in die kerk, hulle weet nie. Baie van my vriende weet toe nog nie daar is twee wat close is aan my wat ek gesê het in die kerk. En toe die pastoor sê hier is mens met Borskanker, ag Kanker ek wil hê julle moet uitkom vannaand. Dis nog voor die kerk basically nog begin het, my vriendin sê vir my “gaan haal jou parcel”. En toe is ons vier vrouens wat daar voor staan en hy het gebid, en alles en ek glo dis waar my genesing begin het, jy weet. Toe die Dinsdag toe, ag toe het ek gegaan vir die tweede operasie ... Dr. B het vir my gesê, weet ek presies waardeur ek gaan en alles. Hulle gaan ‘n bietjie dieper sny, hulle gaan die limfkliere verwyder en dan sal hulle maar kyk hoe die behandeling gedoen gaan word. Die operasie het goed gegaan, ‘n uur en ‘n half gevat. Ek het uitgekom en ek was ‘n bietjie morbied, maar ek onthou, hy was nie seker of hy my bors gaan verwyder of nie ...

L: So jy het daai angs ook gehad?

PA: Dit was vir my ook traumaties, want jy weet nie as jy uitkom, wat gaan vir jou lê en wag nie. Het jy ‘n bors of het jy nie ‘n bors nie? Verstaan jy? Ek dink dit was vir my traumaties en dit het ek met my ma gedeel. En vir haar gesê, ek weet nie wat, dit voel weer dis jou vrouwees was aangetas is, jy weet. En daar is geen beheer, en daar is geen way wat jy kan probeer beskerm of daar is geen manier hoe jy jouself kan help op hierdie stadium nie, jy is afhanklik van ander mense om te weet wat hulle doen.

L : Dis in ‘n mate en iets wat in die temas met die literatuur uitgekom het, jy verloor eintlik kontrole, jy het nie beheer oor wat met jou gebeur nie ?

PA: Ja, ek dink dis die ergste, want jy wil vasgryp aan iets of iemand, maar daar is niks wat jy kan aan vasgryp nie. Jy probeer gryp aan elke grashalmpie om vir jou sort van hoop te gee. En ek onthou toe ek uit die operasie uitkom, ek was nog so half bedwelmd, en Ronel was saam met my ma en die eerste ding sê my ma: “ Al twee jou borste is nog daar” En Ronel ... dit was een van die most ‘embarrishing moments’ van my lewe, maar ook ‘n verligting, jy weet. En toe, wel, toe het ek maar net die dag by die hospital gebly en ek dink vriende en mense, wat jou deur hierdie ding dra is ongelooflik belangrik. Ek het nie besef hoe waardevol dit is tot daai dag nie. Ek was nie, toe ek uit die operasie saal tot die aand 10h00 toe was ek nie een oomblik alleen nie. Mense in en uit en in en uit. Die volgende dag mense in en uit daar was mense wat ek nie eers geken het nie wat

iemand gestuur het wat deur dieselfde ding gegaan het – gaan praat net met haar en so aan. En toe wag ek dat die dokter vir my sê wat verder, nou wag jy vir die resultate. Na twee dae is ek terug huistoe. By die huis gekom, nou wil my ma by my bly, ek wil net op my eis wees, ek wil deal met hierdie ding, basically. My pa het toe latr vir my ma gesê : “Weet jy wat, die kind wil rus, los haar.” Maar ek onthou, want ek weet nou nie, o nee, toe bel my ouma en ek gesels met my ouma in Potch. Toe hoor ek my tannie het Kanker in haar vrouedele, sy praat toe net vreeslik moed in en ek onthou net ek sê vir my ouma ek wil doodgaan nie. Ek wil nie nou doodgaan nie, ek is nie nou reg om dood te gaan nie. En hoe ek by my ma gehuil het, heeltyd, asof sy moet help, nou, jy weet. Iets doen dat ek nie nou moet doodgaan nie, jy weet. En daar is net niks wat niemand of iets wat kan help om te sê jy gaan, hoor hierso dit gaan regtig OK wees nie. En in daai paar dae moes ek cope met toe ek nou alleen is met myself en ek het baie nog steeds baie gehuil, baie emosioneel, jy weet, maar ek het by ‘n punt gekom wat ek besluit het ek kan nie so aangaan nie. Ek moet besluit ek gaan in die Here vertrou meer as een, want dis al wat ek nou kan doen, ek het nou niks om aan vas te hou ...

L: Menslik moontlik is jy deur alles?

PA: Ek is deur alles. Nou is daar vir my geen ander keuse of ek gaan nou in depressiewiteit verval en myself bejammer, of ek gaan opstaan en dis net daar waar ek ‘n besluit gemaak het. En elke keer as iemand my bel en moed inpraat en vra hoe gaan dit nou dan sê ek dit gaan fantasties- God is goed, God is op die troon.

L: Is dit wat jy werklik gevoel het?

PA: Nee, maar jy weet vir jousef jy kan nie altyd vaskyk in die negatief nie, want hoe meer jy in die vaskyk, hoe meer depressief word jy. So ek het iets gesoek waar aan ek kom vashou, iets wat ek weet meer groter is as ek, jy weet. Totdat ek nou by die dokter kom, toe moes ek by die dokter uitkom vir my resultate. En toe sê hy vir my en daarvoor was ek net ongelooflik bang, want ek is vreeslik bang vir waarheid, ek is vreeslik bang vir dit, meer as enigiets anders. En die vernedering van hierdie hele storie, was net so erg vir my.

L: Kan jy dit vir my verduidelik? Die vernedering, wat is die vernedering?

PA: Veral, jy weet, jy moet jousef expose, hier moet ek by die dokter gaan lê. Nou kom ek en hy sê OK ek gaan nou vir bestraling. Hy kan nie chemoterapie vir my justify nie,

want daar was geen vedere Kanker toe hulle die volgende deel uitgesny het nie, was daar geen Kanker nie en my bloed was fine. Dit wat hulle uitgesny het was 'fine', die limfkliere was 'fine' so hy kan nie chemoterapie, maar ek moet deur die bestraling gaan. En daai was vir my erg, dit was 'n jong dokter, ek weet nie wat noem 'n mens hom no weer nie, wat oor die Kanker is, onkologie afdeling. En jy moet uitrek voor hom, en ek is 'n baie private mens, jy weet. Dan teken hy op jou liggaam, nou daar moet die bestraling en dan moet jy na 'n ander kamer toe gaan, daar moet jy weer gaan lê, 'n ander klomp vrouens. Oeg ek dink dit was vir my ongelooflik erg, jy weet. En daardeur moes ek baie gegaan het. Ek dink agterna was dit die ergste vir my om meet te deal. Elke jaar en elke keer as ek moet gaan vir my toetse was dit die ergste om mee te deal, ek was altyd emosioneel. Maar toe ek nou deur die bestraling gaan en jy begin die susters om jou leer ken, was dit vir my makliker om mee te cope, maar ek het myself so gedertemineer dat ek nie sal afsak in depressiewiteit nie. Ek het baie hard met my self gewerk, ek weet nie hoe om dit te beskryf nie.

L: Hoekom sal dit vir jou so moeilik wees om depresief te wees? Omdat dit nie pas by wie jy dink jy is nie? Of omdat dit nie aanvaarbaar is nie?

PA: Ja, in 'n sekere mate was ek bang om dit toe te laat, ek weet waar dit my sou neem nie.

L: Jy het dit baklei?

PA: Ek wou, ek wou glad nie daar kom nie.

L: Don't want to go there?

PA: Ek het vir myself gesê, dis nie waarnatoe ek gaan nie. Ek dink ek het in 'n sterk, soos my ma my groot gemaak het ... Sy sou altyd gesê het, ag dis nie so erg nie, jy weet. Daai tipe van ding en as ek wou afsak was sy daar om my weer op te help. So, jy weet ek het nog nooit in daai diep dip gegaan nie.

L: Maar jy kon dit amper sien?

PA: Ek kon dit voel, sien kom en dis hoekom ek daai dag besluit het, ek kan nie verder as die afsak nie. Nou moet ek beheer neem oor dit wat ek kan. En dis wat ek probeer doen het. Ek het begin na ander mense uitreik, wat deur dieselfde gaan as ek om te deal daarmee.

L: Hoekom help dit?

PA: Want dit vat die fokus van jouself af. Jy sit die fokus weg van jouself af, want dit is wat 'eventually' vir my goed gewerk het, was om te vergeet van myself. Want ander mense se probleme lyk altyd vir jou erger, as waardeur jy gaan en as jy na jouself kyk dan dink jy, maar sjoe ek is gebless. Dit waardeur ek gaan is nie so erg nie. Toe ek deur die storie gaan was daar 'n jong meisie wat net getroud was wat deur breinKanker gegaan het, sy het deur bestraling en chemoterapie gegaan. So ek het sekere mense geleer ken saam met wie ek die pad moes stap, jy weet. Daar was ook 'n ou tannie, haar hele liggaam was versprei met Kanker en sy het eendag vir my gesê: "Hoekom is jy hier, jy lyk vir my so op en wakker en vriendelik en wat." Toe sê ek vir haar daar is iets verder groter as ons, jy weet. En ek het begin uitreik na hulle toe en die mense om my en hulle

L: Genesing gebring?

PA: Sodat een van die dokters, sielkundiges in die onkologie sentrum vir my gevra het of ek nie wil insit as 'n om vrouens wat deur daai goeters is te help. En ek was great dit was vir my 'n, maar ek onthou ook nou, terwyl ek met jou praat dae wat ek deur dit gegaan het, die bestraling en in my kar, toe begin ek werk weer na vyf weke, maar ek moes nog steeds deur die bestraling gaan, dat ek die werk bel en sê ek kan nie cope nie. Ek gaan terug. So daar was die emosionele dae al probeer jy hoe sterk wees, is daai oomblike daar wat jy weer tot jouself kom, wat dit vir jou voel, sjoe dit is erg. En dan het ek huis toe gegaan en gaan huil en weer, jy weet en een ding wat ook goed vir my was was dat ek moes terug gaan werk toe daar was nie vir my 'n, die werk het my nie die kans gegee hoor hier, jy kan vir ewig by die huis sit nie. Jy moet terug kom. Hulle het my alhoewel die fleksie tyd gegee om stadig aan te 'cope', maar toe ek by die werk instap, toe 'load' hulle my.

L: Het dit jou goed laat voel, die feit dat hulle jou sien as net so 'capable' soos altyd?

PA: Sjoe, om die waarheid te sê ek het nie eers gedink aan dit nie. Dit was vir my so overwelming op daai oomblik. Ek dink nie ek het eers kans gehad om daarvoor te dink nie. Maande later, toe ek terugkyk toe besef ek dit was die beste ding wat met my kon gebeur het, maar daar was nie vir my tyd om te sit en top nie.

L: En hulle het jou ook nie behandel asof daar fout is met jou nie.

PA: Ja asof ek deur iets gegaan het, asof ek so lank van die werk af weg was nie. En mense het gekyk na my, omdat ek nooit, nie nooit nie, maar hulle het nie die depressiewiteit of daai emosionele breakdown kant van my gesien nie, want elke keer as hulle met my gepraat het, het ek elke keer sterk gewees en gesê dit gaan goed en opgewonde, vriendelik gewees en so aan. Ek dink hulle was ‘amazed’.

L: Dink jy jy wou nie dat hulle dit sien nie? Dink jy ek is reg? Dis privaat joune. Dis jou pyn...

PA: Ja, ek wou nie hê mense moet sien ek verloor ‘control basically’ nie. Ek dink as ek nou eerlik... as iemand wat hou daarvan om in ‘control’ te wees van myself, jy weet, so dis seker maar.

L: En die mense na aan jou kon jy vir hulle sê dat daar dae was, wat regtig nie goed was nie?

PA: Ek dink my man was eintlik wat my, ek kan nie onthou dat ek so baie met hom gedeel het nie, ek dink daar is ‘n kant van my, wat even hy nie bewus was van nie, wat jy privaat hou want jy weet nie hoe om dit vir mense oor te dra nie. En jy wil ook nie hê mense moet jou bejammer nie.

L: En jy wil hulle beskerm?

PA: Is so en jy wil nie hê dat hulle meer moet oor ‘worry’ as daai tipe van ding, so jy staan sterk vir almal om jou, ek weet. Ek onthou Dan se tannie wat gebel het en gesê; “Hoe doen jy dit?” Want ek het nooit laat val hoe ek voel of daai tipe van ding nie. En vir myself

L: En jou kind hoe was dit met jou kind? Wat dink jy het sy ervaar?

PA: Ek weet nie, want sy was nie regtig betrokke nie. Ons het haar sover as moontlik uit dit uitgehou. Toe ek deur die operasies en goed gegaan het, was sy nie betrokke nie. Sy het geweet ek gaan maar ons het nooit gesê waarom nie, maar agterna toe ek deur dit is het ek dit met haar gedeel. Maar ek kon nie optel dat dit haar, miskien kan iemand anders, maar ek kon nie optel dat dit haar geaffekteer het nie.

L: Jy het haar beskerm?

PA: Ja, dit het nie gelyk asof sy iets agter kom nie, jy weet. Ja dit is ‘amazing’...

L: En hoe lank was die bestraling?

PA: Dit was dertig dae gewees, wat ek elke dag moes gaan vir die bestraling. Ek dink die eerste paar dae was erg vir my – dit was daai blootstelling en so aan. Dit was vir my vreeslik erg. En agterna het ek dit begin geniet om te gaan, dit was vir my heavy excitement – nou gaan ek mense sien wat ek nou gaan help en vergeet van myself, so.

L: Dink jy iets soos Kanker isoleer ‘n mens van ander mense. Dat niemand regtig weet hoe dit is nie. Wat ek probeer sê is daar is almal in die selfde ding en almal weet waarvan jy praat, terwyl niemand regtig geweet het hoe dit was vir jou nie.

PA: Ja ek dink dis hoekom ‘n mens dalk daai gesoek het. Alhoewel ek weer nie myself blootgestel het nie – uitgereik na ander, ek het weer voorgegee dit gaan fantasties.

L: Het jy ooit toegelaat dat iemand na jou uitreik?

PA: Wel, die kerkmense en al daai het uitgereik, maar weer nie daar nie. Ek weet nie of dat dit my, dat ek so goed probeer voorkom dat niemand eintlik gevoel het dis nodig nie. Dit het gelyk asof daar niks met my fout is nie. Ek het altyd gesorg dat ek netjies aangetrek is, my hare gedoen, ‘make-up’ – ek wou nie siek lyk of enigsins iets nie. Die uiterlike was vir my baie belangrik. En die mense by die kerk ook, almal het gekom, ek meen almal het gekom en kos gebring, en so gesorg. Dit het vir my gevoel asof die Here watter gevat het en my in daai watter toegevou het en my beskerm het en my gehelp het dat ek nie afval in depressiewiteit nie. Daar was nie ‘n oomblik vir my, jy weet in daai oomblikke wat ek gevoel het ek voel hartseer en alleen, net sodra ek daar is, is daar ‘n oproep of dit is dit of blomme of wat ook al, wat my net uit dit uitgetrek het. As ek terugkyk en die toetse agterna, jy weet, ek moes elke 4 maande weer gaan vir die toetse.

L: Ek dink dit bring my by die ding van Kanker word gedefinieer as ‘n chroniese siekte. Hoe voel jy daarvoor of sien jy dit as iets wat total verby is? Of is daar ‘n deeljie van jou wat voel dit kan weer terugkom, of hoe voel jy daarvoor?

PA: Die eerste ruk, ek moet sê die eerste jaar het ek baie gesukkel, want dis altyd in jou agterkop, dis altyd. As ek werk toe ry en ek kry ewe skielik ‘n pyn, ek moet sê vandag, partykeer kry ek ‘n pyn en dis dadelik in my gedagtes.

L: Dan wonder jy.....?

PA: Dan wonder ek, maar ek skuif dit net af agter my, jy weet, want ek het vir myself besluit, ek sal gesond wees, ek sal dit nie aanvaar nie. En dis altyd ‘n stryd en dis altyd iets teenoor wat jy moet baklei, regtig, jy weet, want die simptome kom terug, basically.

Dis soos iemand nou die dag gesê het, jy is miskien genees van siekte, maar daar is partykeer symptome wat jou herrinner aan daardie sieke.

L: So dis eintlik altyd half deel van jou?

PA: Soos as jy 'n pyn het, ek weet en ek is baie gesteld daarop ek sal nooit daaroor praat somer nie of so, maar ek weet as ek eerlik is, daar is daai dae wat die simptome daar is en dan is ek bekommerd, maar ek laat my nie toe om te veel daaroor top of iets nie, jy weet. Ek het geleer om daarmee te deel. Ek het nou al gesê duiwel as jy my herrinner aan my verlede dan herrinner ek jou aan jou toekoms, jy weet en dit het my net geleer om daarmee te deel. So ek sê ek sal nie ooit weer Kanker hê nie, dis verby ek het daarmee gedeel en ek het ook agterna gegaan vir 'n biejie berading en so aan om weer te cope en ek dink dit was vir my goed.

L: Soos wat se berading?

PA: Een ding wat my, wat almal altyd sê van Kanker is as jy Kanker het, ek is nie altyd seker oor dit, maar in my geval was dit ook waar. As jy Kanker het, of dit gekry het is omdat daar bitterheid in jou lewe is en onvergewensgesindheid. En ek wou dit nie aanvaar nie, nie ek nie, ek is baie lief vir mense dis ontmoontlik laat ek daai goed in my hart koester. Maar iemand wat ook deur Kanker gegaan het het vir my gesê: "Man gaan net, gaan net dat iemand, jy het deur 'n vreeslike traumatiese ding gegaan en gaan praat met iemand daaroor." En toe het ek gegaan en toe besef ek, ek het regtig issues in my lewe, wat ek nie, ek het dit so ver diep gebêre in jou lewe seker maar met die toegang van lewe en so aan. Toe besef ek ek het regtig bitterheid in my lewe en onvergewensgesindheid en dit was vir my 'amazing'. Ek het gedog, joe hoe is dit, ek meen jy weet jy voel dis onregverdig, jy weet, jy dis nie asof jy dit bedoel om bitterheid in jou lewe te gekoester het nie, maar jy het tog 'subconsciously' het jy dit gedoen, jy weet en dis die prys wat jy betaal daarvoor. En vir my het dit eintlik gevoel dis die prys wat ek betaal vir dit.

L: Amper soos 'n straf?

PA: Ja. En dit was vir my moeilik. Dit vir my het vir my gevoel of ek gestraf is vir iets. Ek onthou ek het baie gebid. "Here vergewe my vir alles wat ek verkeerd gedoen het en so aan." Maar toe ek deur die bevryding goed gegaan het, bietjie saam met iemand gesels

het en so aan, toe het ek vrede met dit gemaak. Maar ek dink dis al die snaakse goed wat deur mense se koppe gaan as jy deur die siekte, ek meen jy soek 'n rede

L: Jy soek 'n oorsaak?

PA: Ja, waar kom dit vandaan? Ek meen as dit nie in jou bloedlyn is nie dan word jy gestraf basically vir iets, jy weet. Is dit miskien die prys wat jy betaal?

L: So dit is belangrik om 'n rede te kry?

PA: Ja... want ek meen jy kan mos nie net

L: En dit het vir jou gepas

PA: Want vir my dit kon nie net gebeur het, uit die bloute 'basically' nie. Daar moet iets wees of ek het iets verkeerd ... ek het heertyd die dokter gevra, waar kan dit vandaan kom. En hy het vir my gesê man jy weet die pil waarop jy gewees het kon dit ook veroorsaak het. Daar is baie dinge wat dit kon veroorsaak het. Is nie noodwendig, jy kan nie regtig pin point waar dit vandaan kom nie. En agterna het ek eintlik uitgevind daar is eintlik Kanker in my familie, baie, jy weet. Maar omdat my ma nie en my 'close' familie daarmee betrokke was nie of deur dit gegaan het nie het ek nie gedink, jy weet dit kan in my familie basically wees nie.

L: Maar jy voel nog steeds dis 'n straf. Dis die goed waarmee jy nie gedeel het nie, weggebêre nie. Is dit waar jy die oorsaak kry?

PA: Wel, daai tyd het ek so gevoel. Ek onthou toe ek net deur die operasie was, het ek baie gebid en gesê vergewe my en alles.

L: En nou?

PA: Ek, ek dink nog steeds dat ek ding in my lewe gehad, soos die bitterheid wat my 'consume' het en dat dit miskien maar... maar ek sien dit nie meer as 'n straf nie. Ek sien maar net dat dit ... hoe sê 'n mens dit daar is 'n manier om dit te sê...verloop van...

L: ...sameloop van omstandighede...?

PA: Ja

L: En jy voel nou bevry deur die hele proses waardeur jy gegaan het?

PA: Regtig, vandag as ek terugkyk is dit, dit klink snaaks om dit te sê, maar dit was vir my 'n voorreg om daardeur te gaan. My lewe is verryk daardeur. Ek het altyd daai gebed gebid die Jabes gebed wat sê "Here verbreed my grondgebied" En die dag toe ek op die bestralings tafel in die middel van my bestraling, 15 dae daarna, toe ek deur dit gaan, toe

voel ek nou het die Here my grondgebied verbreed. Soveel wonderlike mense ontmoet, ek het deur soveel trauma en dinge gegaan in my lewe en ek voel my gebed waarvoor ek gevra het, het die Here vir my gegee – my grondgebied is verbreed. Nie in ‘n slegte sin nie, ek bedoel dit in ‘n goeie sin, jy weet. As ek nou terugkyk, vir my is dit ‘n wonderlike ding wat ek mense wil deel, dit is vir my ‘n groot ding in my lewe gewees. Lewe is kosbaar, my familie is kosbaar, jy weet, ‘n Mens word partykeer nog teruggetrek in die vinnige rut van die lewe hoe dit is, maar vir my as ek terugkyk, daar is ‘n doel in my lewe en dat die Here my daardeur ook gedra het en so aan.

L: Sou jy sê, jy kan nou sit en terugkyk en amper betekenis uit dit kry? So dit was belangrik vir jou dat dit ‘meaningful’ moet wees. Dat jy vandag hier kan sit sê dit en dit is anderste? Of ek dink nou anderste hieroor, of ek is nou meer veryk.

PA: Ek dink so, ek dink vir my wat ek daardeur geleer het, vir my was dit heeltemal geestelik, OK vir my het ek vasgegryp aan die Here meer as enigiets anders en ek het my hele lewe aan die Here geglo. Ek het in ‘n Christelike huis groot geword en alles, maar daar het dit vir my werklikheid geword. Daar het Christenskap vir my ‘n werklikheid geword, want as jy nie deur sulke goed gaan of nie deur die test en trials gaan nie dan is dit maklik om ‘n Christen te wees, maar daar moes ek ‘n besluit maak of ek gaan glo of ek gaan nie glo nie. So, as ek nou terugkyk was dit vir my waar my Christenskap vir my waarde begin kry het, waar ek regtig kon sê die Here het my deurgedra. En dis hoe ek dit sien dis as ek terugkyk dis dalk wat die Here vir my wou leer, jy weet. Hy het dit nie langs my pad gebring nie, want Hy bring nie siekte nie. Maar hy het my deur dit gedra, jy weet. Dis daai ding wat sê:”Ive been past the test”, jy weet. Now the rest is the best, jy weet, so vir my, my future is far better than my past, daai tipe ding, jy weet. So ek glo dat die Here my daardeur verryk het, want ek meen ek het deur ander dinge ook in my lewe moes deal, maar ek dink hierdie was die mees traumatiese ding waardeur ‘n mens moes gaan.

L: Dink jy jy is in ‘n mate vreesloos nou ?

PA: Ek het nou die dag aan dieselfde ding gewonder.

L: Want ek meen dis erg. Hoe oud was jy toe hulle vir jou gesê het, jy was ...

PA: Dis 3 jaar terug, so 36.

L: Ja ek dink dis almal se vrees, ek dink dis elke vrou se vrees om daar te sit en 'n knop in jou bors te kry en iemand sê vir jou dis Kanker – so dis amper die ergste ding wat met jou kan gebeur?

PA: Dit is so. Want weet jy ek onthou hoe ek werk toe gery het eendag dan luister ek hoe vrouens wat huil, want hulle praat oor Borskanker. Jy vat dit nie ernstig nie want dis nie jy wat daardeur gaan nie. 'n Mens dink altyd dit gebeur daar en dit was vir my amazing dat dit van daar af so close aan my beweeg het. My vriende, dit was die ergste vir hulle, want nie meer daar nie, dis 'close', jy weet.

L: En dit maak mense om jou bang?

PA: Ja.

L: Ek weet nie of jy die ervaring gehad het, dat mense amper bang is, want daar het iets met jou gebeur ...

PA: Ja dit is so dat hulle nou die fokus daarop sit. Ek weet my een vriendin het toe knoppe toe daarna in die bors gekry, een van my kliente en dan bel hulle my, jy weet en sê hoe is dit, wat die vrees was. Mense wat dan in jou naby kringe is, is seker meer oplettend daaroor, jy weet. Dit was ook nogal interessant, hoe jy dan daai mense aantrek, wat ook bang is om daardeur te gaan en so aan.

L: Ooit gevoel mense vermy jou?

PA: Nee... Ek voel mense het, ek weet nie of dit net in die kringe is, my vriende en so aan, maar mense was nader aan my, meer 'support', dit voel of hulle jou deur hierdie ding wou dra, jy weet. 'Even' my kliente, ek meen, die base oorsee, dit was vir my amazing, ant daar is altyd 'n soort van 'n formele verhouding tussen jou en jou klient, maar ek meen daar het die 'barriers' gebreek.

L: En die toekoms? Hoe sien jy die toekoms.

PA: Ek is opgewonde oor die toekoms. Ek is so opgewonde. Net om terug te kom na jou vorige ... of ek nie vreesloos is nie... Ek het nou die dag gewonder, wat is daar wat erger as dit kan wees. Want ek meen Kanker is die ergste wat oor jou kan uitspreek.

L: Jy het oorleef...?

PA: Ja, maar ek het al gewonder hoe kan mense dit anderste vir iemand vertel. Want daar is waar jy jou grootste skok in jou lewe kry, jy weet. Soos die dokter, ek meen hy deal met duisende scenarios, hy kan tog nie afbrekend lyk, asof hy vir jou jammer voel, maar

hulle kom eintlik koud voor, die medici. Hulle koud teenoor jou saak, hulle is nie ongeskik of so nie, hulle is vriendelik en behulpsaam en alles, maar hulle is nog steeds koud teenoor jou.

L: Sou jy dit anders wou gehad het in enige opsig. Is daar 'n ander manier om vir jou te sê?

PA: Dis waaroor ek al baie gewonder het. Ek weet nie hoe kon hy dit anders vir my gesê het nie. Ek in myself was spyt dat ek dit so dadelik aanvaar het- die ergste. Ek het agterna gedink kon ek nie net eers voor ek dit gevat het as final net eers 'n bietjie daaroor gedink het nie of bietjie oplees, maar ek was onmiddelik negatief ek was onmiddelik asof iemand klaar dood oor my gesprek het. Ek het klaar begin oppak.

L: Dis een mens se opinie?

PA: Ja, daar het ek onmiddelik klaar die einde gesien. Ek weet nie, ek het

L: Hoekom dink jy is dit dink jy omdat hy gepraat het van 'n possisie van outoriteit?

As die sjirurg so sê dan moet dit so wees?

PA: Wel, hy 'operate' in daai, dis sy platform. Hy die kennis soos jy is afhanklik van wat hy vir jou gaan sê of nie. Nee, dis absoluut so.

L: Enigiets wat jy nog sal wil byvoeg.

PA: Ek onthou nou net dink nou net aan daai drainage wat hulle vir jou insit, waarmee jy moet loop ... dit was ook so embarishing, maar wat ek probeer doen het was om nie my lewe te stop nie – so ek het met hierdie ding wat so 'n lang caterer, ek moes op 'n sekere manier slaap en in die kant van die bed laat lê – dit was vir my 'embarishing'... maar ek is kerk toe met daai ding, so opgerol en in my broek gesit, jy weet daai tipe van ding. Ek het gaan kuier, ek wou nie gehad het my lewe moet nou op 'n halt kom nie – op so 'n manier, jy weet. Ek dink net as 'n mens daardeur, ek het ook met iemand wat naby sterwend was gewas gepraat die dag, toe is ek gediagnoseer en ek wou hom moed in praat, want ek weet hy is naby sterwe en ek dink die heel belangrikste is om net probeer fokus op iets. Jy weet, ek het baie literatuur gelees, baie goed oor, wat my 'n bietjie meer 'confidence' gegee het oor dit is heelbaar dit is geneesbaar.

L: So jy het kennis gesoek?

PA: Ja.

L: En dit het jou 'power' gegee?

PA: Ja en ek het na mense gaan luister wat gepraat het oor Borskanker, sulke talks. En my vriendin het my weer aangemoedig. Ek is nie iemand wat sommers so iets op my eis sou doen nie. Maar die mense weer in my kring het my aangemoedig om sulke goed te doen. Hulle het my sommer net gevat na sulke goeters to en dit het vir my baie beteken, want ek was daar tussen 'n hele klomp vrouens wat almal in 'n seminar gesit het, wat almal het Borskanker gehad. Ons was nie een verskillens van mekaar nie, en daai vrou het gepraat en gemotiveer en vertel oor Borskanker en daai tipe van ding, dit he took baie vir my beteken. Soos daar is iemand wat deur dieselfde ding as jy gaan. Ek dink 'n mens soek eintlik daai 'companionship basically'.

L: En wat ek hoor by jou is jy was nie, alhoewel jy met tye gevoel het, jy is nie in kontrole nie, het jy nie passief gesit en gewag vir die ding om jou oor te neem nie – jy was proaktief.

PA: Ja, ek het baie boekies en my ma het vir my boekies gegee, ek het baie gelees, goed wat my nie sal toelaat om 'down the dumps' te gaan nie. Ek weet, ek het baie gefokus op die Woord, ek het baie goed gelees oor genesing en ek het baie tyd met die Here saam gespandeer. Ek het begin werk, ek het nog steeds gekook, ek het nog steeds dinge gedoen. Ek het myself nie afgesny en dis so maklik en ek dink dit is die ding wat ek wou doen in die begin – ek wou my wegsny van mense af, maar die groep mense waar binne ek was het dit nie toegelaat nie.

L: Jy dit self ook nie toegelaat nie?

PA: Ja, daarna daar was nie eintlik vir my 'n keuse om in die down ... ek wou net aangaan, ek wou nie out of control wees nie, ek wou net aangaan.

L: Hulle sê as so iets met jou gebeur kan jy amper jou identiteit verloor in 'n sin of jy is amper nie meer heeltemal die mens wat jy gedink het jy is nie. Of jy moet amper 'n nuwe identiteit ontwikkel, of jy moet regtig hard baklei om die ou een te hou. Wat sal jy 'comment' op dit?

PA: Dit is absoluut so. Jy leer gou-gou, wat ek gewonder het, is wie is ek; want ek het probeer cope met verskillende... nou wil ek in 'n depressie ingaan, maar dis nie wie ek regtig. Ek het myself gekenmerk of 'n 'label' op myself gesit as entoesiasties.

L: En dit is wat die wêreld sien?

PA: Ja, soos wat hulle my sien wou ek ophou. Daai front wou ek ophou en nie laat gaan nie. En vir myself, want dit is hoe ek myself sien. Daai persoon, sterk, in beheer. Ek ken die Here, ek wou nie toelaat dat mense dalk sien “o nee, sy verloor dit dalk heeltemal nie” So dit het ek vir ander mense, toe ek deur dit, het ek baie sterker probeer wees. Wat, as my vriendin kom kuier om my te bemoedig op die einde was dit ek wat haar bemoedig, maar ek was die een wat deur iets gegaan het. Jy weet, dit is so, dit is baie moeilik om jou saak mee tred te hou, maar ek dink jy het vir jousef ‘n karakter of ‘n label gegee en ek het gefight om dit te hou. Ek wou ek weet nie wat dit is nie ek wil nooit uit beheer uit lyk nie, ek dink daar is ‘n ding in my verstand oor ‘n prentjie oor hoe lyk iemand wat uit beheer uit is.

L: En dit was ‘scary’?

PA: Dit was ‘scary’ – ek wou, oe ek wou dit nie toelaat nie. Want even net toe die dokter vir my sê ek gaan deur chemoterapie gaan, en dink ek gaan my hare verloor, ek gaan altyd siek wees – uit beheer uit wees. Ek kan nie dit beheer nie. Dit was vir my hengse – daarvoor het ek nagte gehuil. Ek dink dit was die grootste ‘challenge’ vir my gewees. Totdat die oomblik wat hy vir my sê “I can’t justify”.

L: En, as jy nou terugkyk, het jy toe beheer gehad?

PA: Nie die eerste ruk nie, maar ek het nie heeltemal afgesak nie. Maar ek het vinnig, ek dink ek het so twee tot drie weke gevat om myself te vind. En toe besef, kyk dis hoe ek dit wil doen en so het ek aangegaan.

L: Ek dink dis dit. Ek dink nie daar is nog iets... ja, wat ek vir jou moet vra is “Hoe was dit om nou te gesels daarvoor?”

PA: Sjoue dis die eerste keer dat ek regtig, ek praat baie oor waardeur ek gaan, maar jy vertel eintlik bolangs – daar was oomblikke waar ek emosioneel was ...

L: Ja, ek ook.

PA: Toe dog ek by myself, sjoue is dit omdat ek vir die eerste keer ‘properly’ weer deel daarmee, jy weet so.

L: Ek wil jou net nie los op ‘n plek wat sleg vir jou is nie.

PA: Nee.

L: Wat dink jy gebeur nou?

PA: Ag, ek weet nie, ek voel nie sleg nie, ek voel glad nie sleg nie. Ek dink net, 'n mens besef nie altyd waarmee jy regtig gedeel het nie, jy weet. En omdat 'n mens baie keer so sterk voorkom, het jy party keer nog seker gevoelens wat jy so diep onderdruk het. So, ja. Ek is so dankbaar vir die Here oor wat HY in my lewe gedoen het. So, al hierdie dinge kom weer deur en ek dink sjoe, is dit regtig waardeur ek is. En ek is dankbaar vir waar ek sit vanaand, jy weet. En elke keer wat ek nog gegaan het vir die bloedtoetse en die goeters. Die dokter het vir my die laaste keer toe ek gaan, eintlik vir my gesê, ons mors mekaar se tyd. Kom jy net eenkeer, nie elke vier maande nie, jy weet. En in die laaste keer toe sê hy vir my in die ag jaar wat hy mense nog steeds toets en soaan is dit die beste resultate wat hy nog gesien het. So, dit het as ek weer deur die goed gaan was ek so opgewonde gewees elke keer, jy weet. Elke keer as jy daar uitgaan is jy verlig.

L: En voor die tyd?

PA: Dis die ergste vir my as ek weer deur daai toetse moet gaan. Weer ..

L: Ek dink dit is waar die chroniese ding inkom. Dit is 'n herrinerings aan 'maybe'?

PA: Ja, dit is wat ek wil afsny, want ek wil nie meer gaan nie, want ek sê nou al, 'n mens mors jou tyd, want die Here het my volmaak genees, so wat wil ek nou daai dokter se tyd en my tyd mors en dis onkoste en al daai tipe goed. En dit is elke keer traumaties, dis vir my ongelooflik – ek haat om te gaan vir al daai toetse, ek haat om te gaan om weer die bloedtoetse is fine, maar deur die mammogram en die weer die sonars, om deur al daai toetse te gaan.

L: Dis heeltyd herrinerings?

PA: Ja en weer by die onkoloog een keer per jaar te wees en weer die toetse te doen ek dink dit is ongelooflik dit is seker maar wat die ergste is nou.

L: Is daar 'n deel van jou wat wil weghardloop en dit net nooit weer doen nie?

PA: Ja ek wil dit glad nooit weer doen nie. Ek was die laaste keer weer by die onkoloog toe gee hy vir my 'n doktersnota dat ek weer moet gaan- ek het nog nie weer gegaan nie, dit was Augustus laas jaar. Omdat ek vir myself sê ek is genees ek wil nie daardeur gaan nie, jy weet. Ja so dit is iets wat ek probeer vermy ten alle... seker want as jy eerlik is dat 'n mens weer op daai punt sal kom, maar ek laat nie myself toe om eers daaraan te dink

nie, jy weet. Vir my is ek volmaak genees, ek sê dit vir almal, ek glo dit – maar daar is dalk I'n seed van daai dat jy wonder, jy weet.

L: Dis normal sal ek sê? Of nie enige teken van swakheid of enige iets nie.

PA: Ja, dit is so maar ek glo as die Here 'n mens volmaak genees het en jy doubt dit dan kan dit weer terug kom en dis hoekom. Dis hoekom dit vir my so belangrik is om dit wat ek spreek oor my lewe positief te spreek, want hulle sê daar is 'power in the tongue', jy weet so wat jy oor jousef spreek so sal dit wees. Wat jy vrees so sal dit wees. Ek is altyd soos as ek die simptome kry sit ek dit vinnig af, jy weet so ek werk aan daai goeters. Ja, sjoe en dit was nou vir my 'amazing' om hierdie gevoelens weer te voel, jy weet.

L: Maar ek moet weet jy is OK?

PA: Nee ek is.

L: My doel is nie om vir jou goed oop te krap nie, maar dit was vir my persoonlik 'n touching interview ook, want ek dink dit was 'n biejie dieper as net die 'content'.

PA: Ja weet jy wat vir my is dit 'n voorreg, sjoe. Ek belowe jou ek voel fantasties. Ek weet wat die Here in my lewe gedoen het. Ek het deur Rumatiek koors gegee, ek en my broer, waar die dokter ook oor ons uitgespreek het en as ek nou terug kyk twee ampere sulke groot goed wat in ons lewens gebeur het, ja daar is 'n groot doel in ons lewens, vir my is dit maar net ek moet daardeur gaan. Vir my is dit wonderlik dat ek vir ander mense en ek het so 'n haat in Kanker nou. As ek hoor van mense wat Kanker het wile k daar wees om te ondersteun, want ek weet Kanker is nie van die Here nie. Kanker is van die duiwel en ek is woedend, ek wil nie hê mense moet suffer nie. So wat ek kan doen om te help wil ek daar wees. So 'n mens kry 'n passie, hulle sê mos as jy deur iets gegaan het, wil jy uitreik na iemand wat deur dieselfde gaan, omdat jy weet waardeur hulle gaan. En dis hoe ek voel daarvoor. Soos 'n meisie wat saam met my gewerk het, toe die eerste ding toe sy dit kry toe bel sy my. En jy voel jy kan daar wees vir mense en iets beteken in hulle lewe, jy weet. Gee 'n biejie sin in die lewe ook vir jou.

L: Dis daai hele ding van 'meaning' kry in die trauma ?

PA: Ja.

L: En dit klink vir my of jy dit gekry het.

PA: Ja-nee, absoluut. Regtig hoor. Ek voel regtig in myself dat die Here ... dat ek genees is. Ek het deur 'n pad gegaan, dit was nie altyd maklik nie. Maar as ek terugkyk ... ek is

altyd bly om daarvoor te praat. Vir my is dit 'n 'testimony' en die ergste is verby ... hoe ek dit sien. Dit kan net beter word. Dis nie om weer daar te gaan sit en daai 'announcement' kry nie, dis verby.

L: Want dit was die ergste?

PA: Dit was vir my regtig die ergste.

L: Ja, ek dink in almal se storie is daar die een ding wat hulle kan uithaal en sê ... kyk ek gaan jou storie herskryf van wat ek gehoor het OK. Dit klink vir my of die nodal point die ding wat die absoluut 'significant' oomblik, daai oomblik was.

PA: Nee, absoluut, want as ek terug dink begin dit altyd daar. Ek kom altyd weer terug na daai punt toe. Daai dag en ek dink as ek dit anders daar gehanteer het dit minder traumaties vir myself gewees het of vir my familie en almal om my. Maar dit was definitief, hoe sal ek sê die hoogtepunt.

L: OK moet ons daar stop?

PA: As daar nog iets is wat jy wil weet?

L: Nee ek is 'fine'. Daar was niks.... Ons het 'n biejie gepraat oor hoe jy die dokters ervaar het, die mense in jou lewe...

PA: Net een ding, ek dink die dokters, soos die een onkologie dokter, ek onthou hoe terleurgesteld ek was in hom. Hy was 'n jong dokter en my medies het alles betaal en soaan, maar daar was R20 uitstaande. En ek stap die dag in sy kantoor in en in die eerste plek haat ek dit om hierdie toetse en goeters te doen...

L: Dis traumaties vir jou om te gaan?

PA: Ja en toe sê hy vir my – “jy hou die brood van my tafel af” – en ek het nooit weer teruggegaan nie. Nooit weer nie, daai attitude... dis nie my skuld nie ek het dit sommer dadelik betaal, maar ek het nooit weer teruggegaan nie en ek het dadelik begin rondsoek om na 'n ander dokter toe te gaan. So ek het net nooit weet teruggegaan na daai dokter toe nie. So baie keer voel ek... en dit was 'n jong dokter ook. Mens wil nie eintlik as jy deur dit gaan soek jy iemand, jy voel jy soek iemand wat meer ervare is. Dis 'n jong man en jy voel eintlik ...

L: Jy moet vertrou hê in daardie persoon?

PA: Dit het gevoel asof hy nie ek sou graag eerder wou sê dit moet 'n ouer man gewees het of 'n dame of wat ook al, maar hierdie ou het my 'heavy' afgesit... net sy 'attitude'.

L: Toe het jy die R20 betaal

PA: Ja en toe loop hy nog voor my en hy het nie die deur vir my oopgemaak hy het amper die deur in my gesig toegeslaan. Net daai 'attitude', nie dat hy dit seker bedoel het of so, maar ek het net gesê ek sal nooit weer teruggaan soon toe nie. En ek wou nog altyd teruggegaan het na daai onkologie centre toe, omdat die een dokter my gevra het om deel te raak van die span, maar ek het net nooit weer teruggegaan nie. Daai tipe van goed vir my is dit... ek weet nie hoe die sisteem ooit sal kan verander of weet of mense meer sensitief teenoor daai tipe goed kan wees nie.

Interview with Dick

L: You telling your story. How would you like me to present you in the study? Who are you? How would you describe yourself? Who are you? What do you do? If I have to say this is ... even if I do not use your name, but this is the subject or the participant this is who he is... What must I say?

D: Well, my name is Dick. I am in the insurance industry. I run a company that I started, six years ago and which is grown way beyond what my original and initial thinking of the thing would be. My original thinking was that it was going to be this nice little company that I have started with two or three and it would be something to carry me through happily into my seventies and beyond. I have no intention of retiring, becoming an old vegetable, who just sits there. So, that is basically what I do.

L: So, what did it become? Very big?

D: It's grown; it is growing all the time. And the trouble is I keep on saying to myself, I do not need it to grow to this degree and if people blame it on my personality type, I can't stop it. You know, I keep on striving to grow more and more.

L: OK. Would you say that is stressful to you? Or is it a good thing?

D: It is stressful; it is extremely stressful. You know what we find as well that competitors in the market tend to set the benchmark on what they are doing on what we are doing. A case of ...

L: Like leading in a sense...

D: They compare to our company, which I would say one can stand and take a bow on, but you know, but that's... the whole thing is stressful all the time. And one of the things that one looks at.... And I think my original idea and thinking of having a staff of two and three and a couple of hundred clients, one of the concerns that I have if I had to, if the business would go backwards, and there is absolute nothing that indicates that it is going to or anything else like that it would be for my staff, that I did not want in the first place.

L: So it is not only your concerns, but other people, caring their concerns as well?

Personally, are you married, do you have children?

D: I am married; my wife is just out spending money somewhere. I have five grown-up children.

L: Are they all out of your home?

D: Ja, they all gone. I have two and a third grandchildren. I have a little boy, who is two and a little girl and the next one is due in August.

L: And what is the syndrome, what is the illness that you have been living with?

D: You know, nobody's been able to adequately describe it. I was through blood tests which discovered the Epstein-Barr virus was there.

L: When was that?

D: That was now 18 months ago and reading everything that I could read about Epstein – Barr didn't actually tell me or didn't tie in to what I was feeling, it was very different. Until a friend of mine is in the medical aid business send me something that had been written and I do not know who wrote it by a American in which he had Epstein-Barr and then a second thing called Chronic Epstein-Barr and it was only when I have read that that I said....

L: Could you identify with?

D: Absolutely, almost, almost word for word. That was written for me and at the end I realised that I that it was Chronic Epstein-Barr. The alarming thing is that the article also made mention of the fact that many people in the medical profession "Coo it" and say that it does not even exist. In looking at things since then and one tends to if you have something wrong with you, you tend to try out to find out as much as you possibly can about it and that type of thing. And it is interesting that I one goes on the internet for example and you type in "yuppie flu" the search, Chronic Epstein-Barr comes up, Chronic Fatigue Syndrome comes up, ME comes up and it seems that the whole, the whole lot is so closely interwoven and intertwined that nobody really is able to tell you to much about it.

L: Do you think you have got the need to pin-point it exactly?

D: No, I don't. I don't. I think what I need to do, I need to, to to accept what I think I have, accept the fact that it is there and I need to try to figure out how... I don't, I don't think that it will go away from other people that I know it is there. And I think one needs to do is one needs to learn how to live with it. And that is what I am busy with myself at the moment, trying to learn how to live with it, how to deal with it. How to manage my life and my time around what I have got. I also find every second person who, who is a

sufferer of the same thing will tell you that they have found some wonderful doctor who did this and somebody else some wonderful diet that did that some one else something wonderful that ... I am not sure that, you know, that that any of this really helps, because I don't know of anybody that genuinely had the same thing that has been totally cured. But I have found people who have learned to live with the problem.

L: And I think that will define it as a chronic illness, because chronic illness we can not cure, but we can manage....?

D: That is exactly what I am working very hard at and I think I kind of identified ... I have identified that it is there, I identified how I feel and I identified what I need to do. For me, the very, very difficult thing, because this all sort of happened in the last month or so, for me the very, very difficult thing now is how to implement that control. And I am battling with that.

L: What are you experiencing?

D: I know that I have to pace myself and my own doctor has said to me and my own psychologist, they both have said to me – pace yourself. It is hard. You know, everybody doctors, psychologists are saying I am a type A personality. It was a term that I never really heard off, till this whole thing. And I guess I am when I hear what a type A personality is – I have no great regrets that I am a type A personality, because I think to be anything other than that, must be awfully, awfully, awfully boring, so I have no regrets, there are downsides, the downside of what I am going through.

L: Do you think you sit now with the consequence of how you have lived or your personality?

D: Ja, the personality definitely, because you know they say that the type A personality who is very very driven. You know, I joked and said I liked to get out of the business that I am doing. Well, it doesn't matter I would not do anything else – I sort of said I liked to have a boerewors roll stand on South Beach.

L: I have also said that a few times, but I will never do it, actually.

D: But if I do it I will like to have a salad bar next door and a ice cream bar on the other side ... I do not know how not to drive....

L: How not to be you?

D: I do not know how not to be me.

L: And you said it happened 18 months ago?

D: 18 months ago it was diagnosed.

L: Tell me before that I mean what was happening to you? That you had to find out what was wrong with you?

D: It started when I realised, it started with a very much stress related type of thing, where I felt that I was not coping - I just was not coping with life.

L: On a physical level or on an emotional level?

D: On an emotional level and I was battling to cope and eventually I reached the stage where I constantly were getting down and depressed and constantly ... I just wanted to run away and this had been going on for 10 months about more or less and I was overseas on business, my wife was not with and I was overseas on business and I was spending time with my daughter and my grandson overseas and this should have been a good time, you know I don't see them all that often, it should have been great and I was just feeling that I was not coping and she said to me, my wife can I please make an appointment to see your doctor when you get home. I said, sure. The day that I arrived I went to see the doctor I sat down, he listened to the whole thing and

L: What did you tell him?

D: I told him what I was experiencing; I told him everything I had experienced in terms of not coping, suicidal thoughts at various times. I told him all that kind of stuff. And he went through everything with me and diagnosed it as this very airy type of thing that you hear all the time 'burn out', 'depression' call it what you like, you know, but you know what I am talking about. He suggested that I go on medication for that, which I agreed to, I am still on that, not the same one. It has changed, but it was the one medication and about four days later and this is not something that I quite understand how, there is was the case of it now reached a pinnacle and it has been identified, but about four days later, I thought that I was going to fall over - I was just so exhausted, absolutely...

L: Like a physical exhaustion?

D: Physical exhaustion, I could not put one foot before the other. I had a meeting and I have been to the meeting and it was a successful meeting so it was nothing special about that and when I left the meeting it suddenly hit me and it was the first time it happened to

me and it hit me big time and I thought I must phone the doctor I must go and see him because obviously it was the medication he has put me on ...

L: It had terrible side-effects?

D: Massive side-effects. So I phoned and they said he can see you in about two hours. And I got to a stop street and if I turned right I could get back to the office, but if I turned left I could go and have a sleep. And this was ten o'clock in the morning. And I went back home and I slept for...

L: Which is out of character for you?

D: Totally out of character. I slept for about a hour and a half and then I went to see the doctor and he said no it is no ways that the medication. I want to draw bloods and drew bloods and it came about three or four days later I got a phone call from his rooms to say he needs to see you and he then said there is reactive Epstein-Barr.

L: What did that mean for you?

D: It meant nothing for me, I did not understand it, I did not understand what it was, I never heard the term, I never heard anything about it at all and he explained in a kind of a way what it was and I said, you know can I have medication for it. And he said no, it is a virus there is no way... And I said what do I do... He said take it easy, just take it easy and if you don't take it easy and you don't switch off your cell phone I am going to stick you in hospital, it is as simple as that. So, I am in the fortunate situation that I have very good strong support staff. I told them that I was not going to be in for a couple of weeks, that I took myself off to Durban, where I did absolutely nothing. Checked in a B&B that overlooked the sea and I did absolutely nothing except sleep for a week, came home and it still went on and still went on ...

L: The fatigue specifically?

D: The fatigue, ja and basically that is the way it is to this day. If I have a very bad and busy week as I have had, not necessarily a stressful week, but a very busy week as I had this last week for example I am finished today, absolutely finished. You know I, Monday for example I was at the airport at half past five to go to Durban, I was back on Monday evening, all meetings on Tuesday, back to Durban on Wednesday, back home on Thursday, yesterday near Hammanskraal for a bosberaad. By the time today rocks around and this morning we were setting up for a big exhibition at the convention centre. And

just before you got here, I was not here; I took a happy little trip to the land of morph. And that is the sort of thing that happens. I know, I absolutely know that is stupid, dumb, for me to have those kinds of weeks. But sometimes they unavoidable and this particular week was unavoidable.

L: Just tell me when they phoned you and said he wants to see you, what were you thinking?

D: I didn't really know what to think, I did not know what to think, I did not know... there was obviously a concern ...

L: I think most people do get concerned if they get any kind of call with bloods ...

D: Sure, sure and you know it's gone... I went and saw him and he put my mind at ease, obviously one is very concerned when you get a call that say doctor want to see you because of blood results. And he put my mind at ease as far as he could. I am in the happy situation that I have a very understanding doctor.

L: Did it helped to have a diagnoses? That they could draw blood and actually find something and that is an explanation for how you are feeling?

D: Yes, yes, because some people I understand they have found nothing. I am at least in the situation, where Epstein-Barr is there, it is active and we know that. That is something ...

L: Was that a bit of a relief? Or was it, there is something wrong now?

D: Well it was, it was a feeling of there is something wrong, because as I said to you just now I never heard the term Epstein-Barr, never, never-ever, and yet probably 90% of us are running around with this virus happily in our systems, behaving itself. I also have no doubt at all that it is because of the way I am and I have been working and stresses and that sort of thing that flared this thing up and caused it to be reactivate, I have no doubt at all about that.

L: But do you feel now sort of responsible?

D: No, no...

L: The message that you were getting was no that you have caused this because you are like this...? You should be different?

D: My feeling on it is that I can't be different. You know in the same way, which in someone is born left handed and some one is born right handed, some of us are born as

driven people and some of us are born as very sort of sedate, mild and will work for a bank for fifty years and happily... that is not me, it is not me and I have no doubt at all in my mind that, that there are penalties if you like, that one has to pay for being a driven person – I am paying one of the penalties at the moment and provided I can come to terms with exactly how I must control it , I will be fine. Yes, I still have a lot to learn to live a bit slower.

L: And then the fact that it is chronic and there is no cure. How do you feel about that? Would it not have been easier if it was something that they could dish out some medicine and...

D: Oh, no, that would have been fantastic- if they could have said take these tablets, one...

L: Because that was what you have expected?

D: Well, the minute he said Epstein-Barr virus and the word virus was sinking in and I realised here we have a bit of a problem; you cannot take medication for it. It would have been an awful lot easier if they had said: you take this medication, take one tablet a day for three weeks and you will be fine. But, having said that, I still believe, I honestly believe that if I can just... I think I have achieved a hell of a lot in the last couple of months particularly and if I can just, that step number one, if I can go to step number two, I will be fine. I will be fine, I will be OK to live a normal and easy life. And everyday, I am doing other things to, to control my, the pace which I am living my life at the moment. You know, this is the kind of thing I am doing, I am trying to do all the time. You know to identify problem areas to find a solution for those problem areas to enable me to live my life to a degree of control and sanity.

L: Do you think you are there yet?

D: No, No...

L: So, where are you now?

D: On a hundred percent trip, about 5km in.

L: What does that mean?

D: It means that I have a long way to go. I have to teach myself a completely new approach to life. But again I don't think this is a massive problem, because, you know we make changes in our lives all the time. You know I have not always been the managing

director of a company and there was a time when I was a filing clerk, many many years ago and as things change in your life and you progress so you make changes in the way how you approach things – this is just another change in my life that I have to got to sort out and when I first became a manager, way back thirty odd years ago I had stuff that I had to learn, about how to do things and this is no different. It is just another development in how to manage myself, at that stage I was managing myself to run an office, now I need to manage myself to....

L: Manage yourself...?

D: Manage myself It is harder, I think, probably the hardest thing, the hardest management change that I ever have to make.

L: So am I right if I say you sort of accept that there is an illness or a syndrome?

D: Yes, absolutely. No question at all.

L: And you realise now it is going to be there forever?

D: For the rest of time, ja.

L: And that requires some changes or ...

D: In my life, ja

L: How do you feel about that?

D: It has to be done. You know, as exactly as I just have said now, thirty odd years ago when I became a manager for the first time, I had to do, make certain changes to be able to do that. I now have to make other changes to be able to do this.

L: And if it is changes that does not fit with who you are?

D: It makes it more difficult. That the hardest part of all at the moment, but I am sitting down and saying what do I need to do and I am looking at it step by step by step by step to be able to, to be able to live with this and to be able to change. You know, I have been saying to myself and I have been fairly, not fairly, partly successful in saying that if I have a week like the one that I have just had ordinarily by Thursday lunch time I would say OK that is me ... weekend now. This week was difficult I couldn't do that. But ordinarily, I can and every time I do that I think that I am making that break through, that step for step. Last week for example I happened, I had to be down in George and I had a bad week then and I had to fly back from George on Friday morning at ten o'clock. Friday morning there was no work involved; anything that was going on in my life was

getting on an airplane and fly back to Johannesburg. I got off the plane at Johannesburg International and I came home – that was my week. With no guilt at all. There was a time when I did have guilt.

L: So before, if you came straight home from the airport ...

D: Yes I would have felt guilty.

L: You not a good worker, you not performing that kind of thing....?

D: Very often I in the kind of crazy situation that ... I was down in Durban this week, I was down there and I was there overnight on Wednesday and I worked, I carry my lap top with me and I worked until I don't know almost half past ten, quarter to eleven at night. I have never have guilt about that. I used to; but that I am beating and I have pretty much beaten that – the guilt thing of saying I am not going to be in the office. But it is just a huge change. I need to manage this huge change and I am slowly, slowly starting to get into it. You know, you said to me just now how far and I said I am five km down the road on a hundred percent trip, so I have along way to go, alarming long way to go, but at least now, what I did not know before at least now I know there is a hundred km trip, where before I didn't.

L: Would you say, because its sounds to me in a way you... there are a bit of change in identity or the syndrome brought in a way a change of identity?

D: It had to, it had to, because if it had not I would have fallen over and...

L: It forced you to...

D: It forced me, if it had not, if I hadn't... I identified with the problem once, I identified where the journey was that I had to take I am now only at the start of that journey, but if I hadn't done that, you know people say to me, ag nobody that they can ever tell has ever died of this unless it is suicide.

L: What do you think if people say things like that?

D: I wonder how, you know I sort of sit and look at it and say I wonder how if I carry on, and carry on and carry on and don't identify what has to be done ... how does this human body of ours actually continue before it falls over. And I sit and look at it and I think, you know, well if I push myself and push myself and push myself I am going to fall over. You know, I don't know whether when if I did that and I have no desire to try and find out and I did fall over what the effects would be then, because it means hospitalisation

and throw the cell phone away and all that sort of thing, I suppose it does, but I have no intention of trying to find out. I have identified the road that I need to go and believe that I am on that journey.

L: And other people, it seems to be there are social opinions about this?

D: There are, there are, you know every second person I, firstly, well... did not go to the other people that are suffering from it...

L: Is it people that you just talk to and happened to realise that they got it or...?

D: For example, to give you an idea, a couple of weeks ago I had discovered that a woman I have known for a long time has it and her kids, it was her fiftieth birthday and her kids stood up and said some lovely things about their mother and in it they made reference to the fact that she had, past tense, ME. And when I spoke to her I said, Jenny, you know Craig, your son said you had ME, from what I understand it is never in the past tense it is always in the present and she said, no I still got it, but what I've learned to do, I've learned to handle life with it. And she said there is some times when I just want to fall over; she said and when that happens, I said all right fine and I clear my diary and I go and sleep for two, three days if necessary and then I am fine again. Somebody else that I know suggested to me that I, I needed to go to a certain dietitian, who concentrates on this kind of thing and I've tried it, cost me an absolute fortune for funny muti and it did 'buggerol'. Somebody else suggested that there is a doctor who draws bloods and sends it overseas and ... I am not going to do that either. Because I have come to terms with the fact that there is no cure....

L: Which is a huge mind set?

D: Ja, so I have come to terms with that and I have come to terms with the fact that I need to change, so one can run around spending large, large sums of money on this doctor and that dietitian and all the rest of it and it is going to achieve nothing other than spending a huge amount of money and I think it begins with me, you know that I need to identify and understand what the problem is and then I need to say, right fine I have to come to terms with this, I've made changes in my life in the past, many times with a whole variety of things and I now need to make yet another change – I've done it before I can do it now. And I think that is... and the other thing you asking about, what is that is the kin of reaction one gets from fellow sufferers....

L: But what about people that does not know?

D: Ja, from people who don't know, you mention to them and it is shock horror, how terrible for you, because I believe its is really debilitating then they get bored very quickly, so you get very, very little support from people who are not sufferers and one of the most difficult things about the whole thing is that outwardly without the exception of extra rings under your eyes, because you are so tired there is no outward sign that there is anything wrong, so the boredom that you see coming from people who don't have it or don't understand it you tend just to say nothing to them, so you, you speak to people that you know who got the same thing or you speak to those who are close to you. I've got a very strong support system at home from my wife and at the office from my, particularly my general manager.

L: So, I mean in a social set up would you ever mention that....

D: No.

L: Not. Because of the reaction...? Not that you have to I am just wondering...

D: I have, I have said in a social set up I have said to people, you know when people said to me – you look tired. I would say, ja, I am tired, this it what the problem is... and they would say Oh dear... And what I've learned is that is as far as they want to know, they don't wanna know They reckoned they got nothing... and as result of that I have accepted that and acknowledge that and respected that, they don't. When I first discovered what I have I was telling people and I have discovered they don't want to know.

L: Do you think if you had anything else that was physically visible...

D: Oh yes.

L: ... there would have been more interest or something people know more about... More phone calls, more understanding....?

D: I have a friend whose had two brain tumors removed and with the same age and his wheelchair bounded and he will never walk again and he can't work any more and that sort of thing all of our friends, we were at school together, all of our friends are very concerned about him, always asking how he is and always phoning him and all that sort

of thing. Ja, most certainly, you know in his particular case, there is suffering one can see, you can see that he can't walk and see...

L: And people know how to react on that or they don't ...

D: They don't. We have a mutual friend that always phone me to say how is Roland ..So why don't you phone him... So, I think that people would react differently if they if it was something that they could see or that they could understand. Because we know that the medical profession does not always accept that it is even there.

L: Ja, that is sort of my question, because there is medical doctors that say it does not exist – it sort of in your mind or something like that...

D: I am in the very fortunate situation that both my doctor and my GP believe that it does exist and I have not yet met a doctor that says sort your head out. One can only wish for them that it never happens to them, because it exists, trust me it exists. You know I am a guy that always been very active, I used to ran Comrades when I was younger, I always been my entire early adulthood I was very fit, very active and this is a very different feeling for me, very different. This morning I said to her we were having lunch, I said to her, I must get home, I was so tired, I must go and sleep.

L: Do you sometimes, I don't know you, but it sounds that you and your wife had quite a good understanding and a good relationship. Do you ever feel guilty towards her.

D: No, I just feel very thankful that she is

L: It must affect her as well...?

D: Yes, it does. She does not fully understand the problem. She is trying very very hard to. As I said to you I have written something on it and she has read that to try to understand more of what the situation is. It must be very very difficult for her, because there is nothing you can see as we were saying there is nothing you can see, you know from it, but having said that she is extremely understanding, extremely supportive and I am in a similar situation with my general manager at the office. It was an eye opener to me when he said I knew there was something and I will always be there, but now I have a slightly better understanding.

L: And what did you write in this article.

D: How it started, how I felt, my reactions, my personality type as I have been told, where to from here, just the whole thing. I also put in there that article that I've got from America on CEP.

L: And doing that, was that like giving meaning to it, or it helped you express it in that way or....

D: Yes it helped there is no question at all that it helped me to, it became after I've written it, I went back to it several times and edited it and after I have written it was as a light had come on and said : now I understand the story, understand what it is, understand how it works. I understand that nobody I have met have a cure for it and I understand what I have to do and how I have to manage it my life from here on end.

L: Because it sounds to me like you are quite a logical problem solving person ...

D: I tried to.

L:... there is the problem, you will think of strategies and you will handle it and it seems that you have done the same kind of thing with this, because it is such a airy fairy fluffy thing and now it happened to somebody like you ... you know you want to know what is happening, you want causes that sort of thing, so by writing that article you could reflect on that...

D: Ja, no question at all and it certainly did help. I have always asked myself the question all the way through life as friends of mine, because we are not teenagers anymore and you watch friends having heart attacks and diagnosed with cancer and ... you always wonder how you are going to respond to it ...

L: And you fear that ... most of us fear that in a sense?

D: No, I don't think so. I often wondered how I would respond. This has taught me how I respond...

L: And what is your conclusion?

D: My conclusion is that I can...

L: You can control things?

D: I can handle it, not getting it right yet and there is sometimes that I fall horribly , horribly , horribly short and it is almost like when I think back thirty odd years ago with my first management problem, I knew that I could handle it and I did not always was getting it right and it is a similar kind of thing. I know I can handle it, but I am not always

getting it right and as time goes by and bear in mind I am a fairly new sufferer, things are going to get better and better.

L: So, the future, how do you see the future?

D: Fine, productive, but slower.

L: And is that OK?

D: It is fine. It's find I just don't ever want to be in the situation where I am...you know I remember when my dad was forced to stop working, he just went downhill until he died, very fast. As a result of that I can't imagine myself retiring, being a pipe smoking old man sitting in a rocking chair in front of the fire; I just don't see myself that way at all. I am still relatively active if I am well I am going to be active, I still ride a motorcycle all over South Africa, I still drive a car all over South Africa, I still do business all over South Africa and I am certain... I am OK. I just got to learn to pace myself that is the biggest struggle that I am having at the moment.

L: So what you saying are that you basically integrated what the syndrome asked from you? Integrating it into your life?

D: Had to, I am trying to. You know, I sat down a couple of weeks ago, and and looked at some of the things that are causing me stress and address that and I already found that that has helped. I am not a hundred percent sure that in the very near future I am not going to drop to a four day week and just say the fifth day does not exist. It is fine to try and recover from the four that I had. But when I am working I am not an eight to five person, you know if I happened to have things to do, I do them and you know I mention the other night in Durban I was working to eleven 'o clock. I had things to do; you know I had to get work done. I carry a lap top with me and if I can I work on airplanes, I work on the airport while I wait for a plane. So I have no guilt at all about the amount of work that I do, you know because it is not a big deal for me to work 16, 17 hours a day it is not a very big deal at all. But on the other side of the scale I also have to come to the understanding that it is fine to work a four day week or a three day week or a five day week – just control it.

L: Let's say this did not happen and you were able to continue with seven day weeks an 16 hours and that kind of thing ... what do you think would have happened?

D: I probably would have had a heart attack.

L: Why do you say that?

D: I think with nature – you don't mess with her and when people work to that degree something happens; I guess I am lucky, I guess I am lucky, I guess this is what happened to me where as other people just have a heart attack and cheers....

L: You referred to your dad, did he stopped working or worked...

D: He worked to 73 and then he had to stop and he just never I have no desire to sit and ... I am in the situation that pretty much now and this is something that will happen as I pace myself more and more that if I wake up today being Monday, Tuesday, Wednesday, Thursday, Friday and know that I have a clear diary I will just phone into the office and say, listen I won't be in it is a lovely day I going to take it off.

L: Is that not quite like... freedom?

D: Yes it is. It is like being retired, but being paid for it.

L: Ja, and still do the things that you actually want to do and still be that person but on different terms?

D: Yes it is, like I said the only thing that I have to learn now that it is perfectly OK to work a three day week or a four day week depending on what the three days or four days before would be like. And that is where I struggle. This week as I say has just gone horrendous absolutely horrendous. Next week I am on leave I am going to do nothing. I am even leaving my lap top behind. The week after that between Chris... ag Easter the long weekend between Easter I am going to work two days, that all.

L: And you OK with that?

L: If I talked to you let's say three years ago would my experience be different?

D: Yes.

L: Can you explain that to me?

D: I would not for a moment thought that I would say I am only going to work two days this week. I was building a company and I was pushing very, very, very hard. If I was not at the office there would be guilt, because I was not at the office and my staff was there working very hard, so all of that kind of stuff have changed, so I all of those kind of things I have come to terms with now.

L: Do you think the illness forced you to?

D: Yes, I think it did.

L: So in a way it empowered you, I know it was disempowering...but on other levels it empowered you?

D: Yes, you know... I know a woman in Durban whose got a similar kind of thing and she is allowing this thing to beat her, because she refuses to pace herself, she sees it as if she does not work a full week...

L: It is a weakness...?

D: ...it is a weakness, where as in fact I think it is the other way around. I think this horrible voice that sits insides us loves it when we drive ourselves to the point of falling over. And you know her approach is that as a result she is in a very much worse way that I am, I mean if I get if I get a very bad time and I get to lunch time and I am tired I will just quit.

L: So it sounds to me that you may be further down the journey?

D: Further that five km... I don't know. It is not easy and there is a lot of stuff that I need to there is a lot of stuff that I still need to work on, there is a lot of stuff that I need to work on very hard.

L: Let's say we have this interview in a year's time, where would you be?

D: Where would I like to be? I would like to be at least on my 100km trip, I would like to be at least at about 60-70 km...

L: And what would that mean?

D: It would mean that, it would mean to me that I would be, that this whole thing would be under far more manageable levels than perhaps now, but even now it is more manageable than it was a year ago.

L: Are you talking about physical stuff or you changing to it.

D: The physical stuff.

L: The physical stuff ... OK.

D: You know I have no doubt at all that the fatigue is worsened if you hammering toms at it all the time then you become unproductive anyway, so I would like to be in a situation where I can completely and absolutely learned how to manage my time to sort this thing out.

L: Anything else that you would like to add to your story?

D: I don't think so, I don't think so I would say I come to terms with the fact that it is there and it is probably not going to go away; I have come to terms with I now understand what I need to do and I think that is a massive breakthrough, for me anyway and I now just need to implement that. And I have already started, perhaps you right, maybe I am more that 5km down the road.

L: I don't hear any denial from you – so that part that you say you have accepted it I hear that and that is a long way, because a lot of people with chronic illness it takes a long to get to that point. And you also seem to make some kind of meaning out of it, some kind of positive change in your life, it is not all negative.

D: No it is not all negative.

L: There are actually a lot of positive things that I am hearing from you – how this affected your life.

D: No it is not all negative at all. It is negative from the point of view of what it has done to me physically, no question at all about that, but from the point of view from the way in which... you know I am 58, so when people get to 58 they supposed to have made it to a very large degree, your kids have grown up, you don't owe anything anymore very much and that is the way we are in terms of a state of living.

L: And you feel you are there, you have made it?

D: Ja, ja despite to all that happened to me in life, despite all of that and the stressors that I had in life would be massive, absolutely massive. I have been in the divorce court more than once, so the stressors have certainly be there, but despite all of that I have caught up and passed many of the guys that I was at school with and that did not happened by chance it happened because of hard work, but having said that there has got to be some reward for it and I think that, I don't know, maybe one can be totally philosophical about it and say well, maybe this came along to say to me this is reward time now.

L: It depends on how you see it; you can either see it as a bit of cheating, you have worked so hard and now that you at the stage that you can actually enjoy it now you sit with the physical consequences, if I can put it that way....

D: No, No...

L: That is one way of thinking or you can in another way that it made you look at your life and assess where you are and sitting a bit back and reflect....

D: And I think that is perhaps where I am that you know that maybe, maybe I don't know, I don't know, I mean, I don't know, but maybe it is a situation where if I had not slowed down and I had not been forced to slow down that I might have just killed over with a heart attack. So maybe, maybe this is a massive, massive blessing in disguise, I don't know. But I come to accept that it is there and know what I need to do and I am now trying very, very hard to do that.

L: Last question, how would you know if you totally manage this, how would you know if you are at the end of the road?

D: The fatigue would tell me, the fatigue would tell me. It would not be as constant as it is. It would be there but not as bad as now. I would not get to a Saturday and be wondering around at Cresta and say to my wife I got to go home and sleep I am going to fall over.

L: So that is how you will measure progress?

D: I think that is how I will measure progress. In fact it is only now talking to you that I think maybe this is nature saying to me listen you have made it just enjoy your life now. I don't know...

L: Anything else?

D: No, but if what I found out about myself through this that can be used in anyway to help others...

L: It will also make give you meaning? We want sense we don't want things to happen to us that...

D: No, one of the things that I have said in the article that I have written .. I will send you a copy. One of the things that I said in that article, you know, if I were an alcoholic or a drug addict there are dozens of support groups around, but I don't know of any ?

L: There should be...

D: There should be...

L: Your psychologist should know, she did her doctorate on this.

D: She had heard of one that was very anti the medical profession, because the medical profession, some of the medical profession ...

L: Ja, there is different opinions.

D: You don't want to put the whole medical profession in a box and say we hate you all.

L: And your experience was not negative in terms of how the professionals had handled you?

D: Not at all, you know I see my psychologist as you know and my doctor is Dr. C, you know him and I have been fortunate that Dr. C no question at all in his mind that this exists. So I have got two people that is saying, ja it does exists. Against that, I have got a colleague who does all of our hardware computer hardware, who is also got CEBV and these doctors said sort your head out. And as a result he is running around taking all sorts of weird and wonderful ..

L: So it is important to have an diagnosis..

D: Yes it is important, some people has said to me how do you know, well blood tests shows it the thing is very reactivated and it is there. I think there are some people that are suffering from this and have not had any diagnoses they just know they feel absolutely awful, like this woman in Durban that I know she feels dreadful, constantly dreadful, and her depression is massive, but she won't, she is still driving herself all the time, I don't think she has come to terms with the whole thing, where as I believe that I have come to terms with it. I believe that I just now have to manage myself.

L: And then, talking now about it, I would just like to know what the experience was like?

D: It was fine, because I already put it on paper.

L: You have already expressed it.

D: I have already expressed it, so it was fine and in fact what I found when I was expressing on paper that I came to terms more with it that I understand what I needed to do. Talking to you has actually gave me another understanding that I did not have before when I put it on paper, that maybe, maybe the Man upstairs said well maybe he must slow down or get a heart attack.

Interview with Gloria

L: If I have to present you in the study. Who are you? How would you describe yourself?

G: In terms of personality?

L: Ja, just, if I have to say this is, I do not use your name, but this is the person story – who is that person? How do you see yourself?

G: Ordinary?

L: OK, an ordinary person?

G: Intelligent, ordinary, busy, sporty – I don't know...

L: Are you married? Do you have a family?

G: Oh, ja, yes, married, two children. Came from an ordinary background, don't know what else? University educated.

L: Just in a nutshell, if I had to present you, what would you like me to say?

G: An ordinary regular person...

L: OK, that is fine. Just tell me about your illness, your experience of your illness.

G: Well, I think if I have to have any illness I would prefer to have this one – at least I can control it. It does not control me where I think lot's of other people's illnesses control them.

L: I think that is a very significant point.

G: Well, to me it is. I would not wish it on anybody, but I rather would have this one, because it is possible to control it, it is not something you lie down and go oh God, I am a diabetic that is the end of my life, you know, as far as I am concerned it was something that came that I don't know how or why, it's not in my family, but perhaps that is not even worth worrying about how or why. It is there and ja I can control it, so...

L: So, although it is chronic it is controlled.

G: Yes. It does not control me. Where I think a lot of other diseases one does not have the opportunity.

L: One of the themes that came out of the other interviews was that feeling of I am not in control – I can not predict this thing. This is what came out of the other interviews were a sense of loss of control and you are coming with something different. How long have you got this?

G: It is either ten or twelve years, I don't really know, because it is not something I think about too often- you know that I think, Oh my God I have been a diabetic for how ever long, it is just, it is there, I have it, I deal with it and I get on with life.

L: This feeling of control was it always like this or is it something...

G: No it is always. As soon as I knew I had it, in fact I found out... my eyesight thing ect., ect and in fact my eye specialist said to me there is a problem and I was in hospital for about three to four days and then went to England, because...

L: Was that when you were first diagnosed?

G: Ja, ja, because as far as I am concerned these things just happen and one gets on with it, it is not something that I feel negative about. It does not impact my life.

L: Or you don't let it?

G: I don't let it.

L: With the diagnoses at that stage, were there any, you said something, like it is not in your family – were you blown over...

G: I was surprised, I was very surprised.

L: Because you have said you were a sporty person ...

G: I have never been overweight

L: You seemed to have a healthy life style...

G: Yes, yes all of that. So I was very surprised, but one sort of go through the initial surprise of it, there was a period of about four months where – the GP's are completely useless, they are completely useless

L: Who diagnosed you?

G: It was actually my eye specialist, he said to me there is sugar at the back of your eye and I went to my GP, who I subsequently changed, because he was even more useless.

L: Define that. What was your experience of that?

G: They did not know how to cope with Diabetes, they did not know enough about it, they just stuck me in hospital, because I dehydrated quite badly, I then saw a physician that came to see me in hospital, he, he, when I look back on it now, he knew nothing, nothing about Diabetes, giving me bad advice, he was, you know, they don't know how to control it, they don't know anything. And then a dietitian saw me...

L: And this is like ten years ago?

G: Ja, ten or twelve years ago. The dietitian also was just floundering, trying to make me eat this and that and the next thing- that was all just absolutely wrong. I can't speak for other people who are diabetics, but I know for me certain foods I do not eat.

L: Was it like, this is the way you treat it and this is what you have to do? And nobody was listening to what you are experiencing.

G: No, there was no personal, individual treatment.

L: This is the recipe

G: That is what you do.

L: And you resented that?

G: Well, it was just ridiculous, because I could just see my sort of basic common sense said to me, this is not going to work. I knew nothing about Diabetes; I started reading up about it. I then was going from one person to the next, speaking to people. I ended up at I think it was B-Laboratories, I am not quite sure which one it was now, it was a long time ago and the woman there spoke to me and she was quite intelligent and clued up on it, but the fact of the matter is that I don't believe that people, unless they are very, very clued up, unless they are diabetics, I don't think they can actually hand out advice, because it is such an individual thing and eventually she said to me try to get hold of Dr. D at the medical school. He takes private patients and I phoned and I have been riding, and they have been telling me all sorts of things, like exercise will bring down your blood sugar – its rubbish, I get into my car after being on a horse for an hour and a half, my blood sugar was in the twenties some where-its rubbish. I was told so much nonsense by people and these were medical people. I got through the one day and phoned medical school and spoke to Dr. D and he said he was terribly busy and I said look I have been told this and this and this and I told him all the things people told me and I said I just got off my horse and my blood sugar was 25 and he said come and see me on Friday, I will make a space for you – and I have been with him ever since. And he knows what he is talking about he tailors it to the individual he listens to the person, you know, they have a lot of ideas about what diabetics should it and how they should eat and when they should eat and my attitude was that instead of my pancreas being in my body it was now in my handbag and

Dr. D said to me – eat what you like, but you got to understand that every time you eat you have to take insulin, each time you take insulin you get fat so you have to sort yourself out. You will find certain things that won't suit you, like grapes and bread and various other things, mango's, I adore mango's, I can't eat them and through trial and error you will find out the kinds of food that don't suit you and if you want a piece of chocolate – you have it, but cover it with insulin, you know. So he was quite happy, he did not have this ... and I went to that dreadful place in

L: The diabetic clinic

G: But, how dreadful, absolutely dreadful...

L: Why ?

G: The one, I have forgotten her name, she was hard and fast, you don't have olive oil, you don't have this you don't have that, I mean olive oil is good for you – you can't have this, you can't have that...

L: So what they prescribed did not fit with ...

G: my life style or my common sense and then of course they prey on these people and there is this big pantry with diabetic stuff in it, that costs a absolute fortune – you've got to have diabetic jam, you've got to have diabetic this and diabetic cake and diabetic biscuits – I don't want any of that stuff and then she said to me if you don't, you have to come to us to have a pedicures, because your feet is going to go gangrenous, you know this whole fear thing, control by fear...

L: Which I think Diabetes... that is what medical people tend to do, if you don't do this, this will happen to you...

G: ... they don't tell you what to do to stop it from happening – none of them are glued up on it. And I said to her I am not coming here to have my feet done, I have it done by Victor... I always have a manicure and a pedicure. Oh no, you have to come to us, because we have to look for this and look for that... and I thought this was a money making paradise, just heard the cash machines making 'ching' every time some one walks through the door.

L: So you felt exploited?

G: I thought it was disgraceful. I thought it was an absolute disgrace, they keep people in a constant state of fear, so they can't think for themselves and everything is pay, pay, pay

and I saw people this size who did not look as if they were getting on very well at all with what was happening and I have been to this place first and then I ended up with Derrick and I said to Dr. D it is the most dreadful place I have ever been to. It's a place of negativity and fear and anxiety, there was nothing positive, nothing encouraging, nothing, you know, this is not the end of your life, we can get through this – nothing like that. She was worse than the Gestapo, dreadful and I never went back again, so, you know it was then a case of trial and error, it is like fine tuning a video machine into you TV, you know. And he, as new insulin came through he was putting me on them and one, the night time insulin that is out at the moment is absolutely amazing, the one before that you get a low at 3 o'clock in the morning, no matter how careful you are...

L: And you trust him, I get the feeling you can experiment with him.

G: Totally, totally. Yes, I trust him completely and utterly. And you know, he, I will tell him what I have eaten, what I have done, I have tried this, tried that, that was not so good, that worked very well and he, because I am very controlled I think he is quite happy to experiment with me, so if a new one come up we may try it.

L: So he trusts you as well?

G: Ja and he pushes, you know he says 7 is perfection and you at 8 now, lets look at 7 point something, so he keeps pushing, he does not sit back and say- oh well you are at 8 OK I am happy with 8 – he goes no, no 7 is perfect, so yes I trust him enormously. If he had to leave the country I would be very sad about it. And so, you know, it is not a disease I would wish on anyone, but if I had to have one I would have this one. Because I feel that I am totally in control – that is the positive side. The negative side is that I don't tell anybody.

L: But why?

G: Because people have such preconceived ideas about diabetics.

L: What makes you say that?

G: The things people had said.

L: Like what?

G: I was out on my horse the other day, with a girl, who don't seem to be very bright, but she is very sweet and we were out together and I was moaning about my husband about the bloody mood he was and stuff, first thing she, and nobody knows I am diabetic and

the first thing, she turn around and said to me – is he a diabetic, and I said no, what has that got to do with anything, oh, you know diabetics got mood swings. And I thought this is so typical, you know, I was with, when I was diagnosed my kids were still at school and I was lift clubbing, lifting with another woman and I did not want to tell her, because they think you are going to have fits at the wheel of the car and black outs and maybe some people do, but it is this negative attitude if you are a diabetic, when if you do something strange – cause she is a diabetic. Or they see you

L: As very emotional...?

G: Yes, because you are a diabetic and you sitting with a fat milkshake and they look at you – you should not be eating that or why not, because you are diabetic or mind your own business, if I want the milkshake I will have it. So there are such preconceived ideas about it and my mother is the worst, my mother, oh my God, she goes on ... I now have banned her not to talk about it. She is not allowed to mention the ‘D’ word. She will start with – oh but you are a diabetic- I said what has that got to do with anything- no, but you should not be doing this and not be doing that and I said who says so, I ride a horse everyday, I go to gym, I do ... my gym instructor does not know I am a diabetic, I will never tell him, because he will start saying – oh you better not do this...

L: So people treat you differently?

G: Differently and as I say I am a very hyper person, I get things done and I got a 21st coming up on Friday, Saturday and you know I am always like that, I have always been like that – I can’t sit still, I don’t go to movies, because I can’t sit there for an hour and a half or two hours I develop... You know, my mother – oh well you should do this and should you not rest And fuck just leave it, it has nothing to do with anything. I get on with my life and you know I am not hyperactive, because I am diabetic, maybe I am a diabetic because I am hyperactive. You know, I don’t know I have always been that way. You’re in a bad mood – because you are diabetic, so I don’t tell a soul...

L: It is a label?

G: It is a huge label. And my very close friends know and nobody talks about it. Because there is no reason to. Why must everyone talk about it? I don’t walk around going; you know I am a diabetic. The one occasion I went to gym and I could feel my blood sugar was dropping, sometimes it just does, I am very good with you I make up my five meals a

day, but sometimes I just did not have a meal, I was just too busy and then it drops and the one day I went to gym with a Coke and he said to me –oh why do you have a Coke and I said I did not have breakfast this morning so I just got the Coke cause I might get a bit dizzy and I've never used it, but I don't tell a soul, as I say my friends do not ever talk about it, because there is no reason. My husband, my kids as well they forget, you know, I don't see it as a big thing. I do keep Coke in my cupboard next to my bed and I've got Super C's in the drawer next to my bed and sometimes with these new insulins it just keeps your evening level on a completely even key the whole time, but on the odd occasion I take too much insulin at night or something and I just have Coke or some Super C's – it is not an issue, no one is running around lights on, getting this, getting that. So I think, so much of possibly any disease is just the attitude, isn't it. If one has a positive attitude it makes it easier. I am sure some people use it as a crutch maybe, I don't know, but I don't like anybody saying anything about it, talking about it, because it is just a non-event as far as I am concerned. I just hope for my kids' sake, none of them get it. Dr. D says its 50% of me and 50% of my husband, so it is diluted and you know the other thing of course is that they don't know what causes it. He has no idea; he says the current thinking is it's a virus.

L: I don't get the sense from you that you ever had to get an explanation?

G: I would have like to know.

L: You would have liked to know?

G: Ja, I would have liked to know.

L: Because it would have made sense?

G: One wonder why, what did I do wrong. Did I do something, was it something I've picked up or was it just my genetic make up. I can't do anything about any of it.

L: But it would be good to know?

G: It would be interesting. It would be interesting and when I was asked to go to a chap in Midrand they want to do transplants – you know the island cells. And I went to speak to him about, they wanted guinea pigs, basically and I decided no. And I know they have done one in England and I think they have done one in America now, a guy who was very uncontrolled by the sounds of it. He is now not using insulin has not for a year, but he has to take so many drugs to stop the rejection- I rather just take the insulin. I was

saying to my husband, you know, which is going to be worse, taking the insulin which is a natural product or taking chemical drugs to stop rejection. So I don't know if they ever going to, I would imagine its probably going to be a genetic modification to try and fix it, but ja, I would not mind knowing why, but you know ten or twelve years down the line it does not really matter, does it? If it were genetic, I would worry about my children, I am sure it is a genetic thing, I am absolutely sure about it, some sort of malfunction or a bad wire or something like that, but I don't know if I am a suitable subject, because I can't moan and groan.

L: Ja, it is your experience. I am just wondering, because there is this constant reminder of Diabetes....

G: Ja, but you just get on with it....

L: ... where with other illnesses you can sort of go into denial an not go for the tests ...

G: I can not go to Dr. D, I suppose, I see him every six months.

L: ... imagine it is not there, but with Diabetes...it's a constant reminder.

G: Ja, but it is not a big deal, I mean you just get your life together, you know, I just go to the loo, test my blood sugar, take insulin if I need to and that's that. So it is not an intrusive thing, I don't have to do this or have to do that every hour or something like that, so ja it is there all the time, but it is not, it is not – I don't find it particular intrusive and ja, I could not go to Dr. D. I do get stressed when I go to him, because I am a perfectionist and I want to do things right.

L: So why do you get stressed?

G: Because I got to have my blood sugar right and I got to have my long-term number right, because I try very hard, so....

L: And if it is bad?

G: Then I am unhappy. I have to try harder. Because it is my health, I am doing it for me not for anybody else. I don't want to lose my vision or my toes or my legs or my kidneys or whatever.

L: Part of that is sort of there in the sense that you....

G: I am aware.

L: You are aware that there are consequences and it is chronic and it can get worse...

G: Only if I let it.

L: If you lose control?

G: Dr. D has said to me if I do it right, I will not have gangrene in my feet and kidney failure and eye sight problems. I am 51, my eye sight will get problematic, but at the moment I don't wear contacts or glasses and I can read a phone book quite happily. So, you know, the eye sight I don't see as a issue, but yes my kidneys and all those other things, if I don't look after myself they will go array and so I want to look after myself.

L: So I get the sense from you, you took full responsibility.

G: Absolutely. Who else is going to? But at the same time, if I wanted to have a glass of wine, I have a glass of wine, if I want a chocolate, I have a chocolate. I don't do it very often, because it is just such a 'slep', you know you have the chocolate and then you have to take so much insulin and all of that, so I don't do it very often, but if I want one, I will have one – I am not going to go, no I can't, but....

L: Guilt? Would you feel guilty?

G: No, because if I I was born without a guilty conscience; you know if I am going to do something I am not going to feel guilty about it. If I am going to feel guilty about it I am not going to do it.

L: So you make the decision.

G: I make the decision. I am not going to do something; oh God I should not have done that and that applies to everything in my life. If I am to do something I am not going to feel guilty about it. But if I think I am going to feel guilty about it something...

L: Then you rather not...?

G: But I am not going to put myself through the stressors, you know what I mean. If I want that chocolate I am going to eat the chocolate and I am going to enjoy every little chew – and that will be that. Its over. But I take responsibility for it, you know, I've got to, no one else will.

L: And you got to that point very quickly. It was not a process.

G: No. Life is to short. I can't sit back and go-oh gosh, or I wish, or I should have, no.

L: So you were sort of early forties, late thirties. Do you think if you got it earlier in life, you would have been more rebellious or more...

G: I don't know. I think I am that sort of a person. I love life and I am busy and I enjoy every moment of this – I can be dead this afternoon or tomorrow. So, and I have always

been like that. So you know, whatever sort of gets thrown at me I deal with it, I am not going to sit down and feel sorry and sulk...

L: And that gives you the control?

G: Ja.

L: Do you think, if I listen to you seem to have a very full life?

G: I try and be busy.

L: You busy, you are doing things. Do you think you are more aware of life because of the Diabetes, because it gave you a sense of...

G: No.

L: It is who you are?

G: It was just sort of an irritation along the way. No, I have always been like that, the Diabetes did not suddenly make me think of my mortality.

L: So it was not as you had to make meaning from it? So it was not a meaningful experience in the sense that you look differently at life.

G: No. No, it was just an irritation came along like a thorn in one's side. Now I had to deal with it. The thorn you could pull out, this remains.

L: Constantly you have to deal with it?

G: Well, you do, you do. But then you constantly deal with life, don't you? That does not go away. So, ja, you know it is just another aspect of life. You must just get on with it.

L: Do you ever talk to other diabetics?

G: No, I don't want to listen to their stories. I really don't. You know they send me, oh God, it is like parasites, they sort of like leeches they get hold of you and they won't let go. And how some one got my address, I don't know, but I got send this diabetic magazines, which got the most appalling horror stories in there, well I told them that I moved, because they would not stop sending it. And then we did move, so I presume the other people are still getting it, I don't know. I don't need to know that, I don't need to know other people's horror stories; you know I am just not interested. I definitely don't go to support groups or speak to diabetics about their nasty problems, no. Just get on with it. Do a lot of people do that?

L: I think it is a personal thing. The literature on Diabetes supports that people do go through a process and that is why diabetics are seen as very difficult, in the medical

world – difficult people to work with, that’s that label again, because they reject a lot of things and be in denial and never really comprehend or integrate...

G: Why? It is their own life they dealing with.

L: I think it is a difficult concept, if you really think about it; it is something that is part of you for the rest of your life...

G: So is an ingrown toenail, maybe not, you can pull it out. I mean so are lots of things.

L: And that is why a lot of people don’t do what you do in terms of taking control over it, rather avoid it and never deal with it effectively.

G: You see, I can not understand that, because the consequences of that are going to be life changing, if they don’t take control. I just do not understand that and there quality of life is appalling. You know, this man that I saw on TV that had this eyelid implant and he could not do sport and he could not do this and I sat there watching and though what is this about, why could he not play sport, why could he not walk down to the shops, why could he not do all this? I am flabbergasted by people like that. Because it is a lack of self-control, is it not? You don’t have the self-control to deal with it, so they just go and sit and moan and have a dreadful life. Nobody, OK, my dentist knows, no my dentist does not know, no my dentist does not know, my doctor knows that I am diabetic, nobody else knows-why does my dentist needs to know? He is dealing with my teeth, you know, if I was going for an operation and maybe I will tell him, but even then I don’t think it is necessary. Because it is such a nothing event, is it not? It is not making changes to anything it is not doing anything, it is just sort of there, you know....

L: Although it does impact on you everyday?

G: Ja, but it is not a huge thing. I don’t drive in my car thinking what I have to do in the next three hours and so on and somewhere along the line I will go, after lunch I will go and test my blood sugar, but ...

L: Am I right if I say that you are quite a disciplined person, anyway?

G: I think I have no self-control, what so ever, to be quite honest.

L: But is does not sound like it, because it is a very rigid thing to do on a regular basis.

G: If I had self-control I would not have milkshakes, I would not have chocolate, I would have been perfect, but I am not. I would not, over the weekend I drank a glass of wine and I had a very upset stomach for about four hours afterwards. If I was completely self-

controlled I would have not had it, would I? So, my husband thinks I have enormous self-control, because I had no alcohol for six weeks. He says he does not think he could manage no beer for about three days.

L: Do you think he sees you as a disciplined person?

G: He does, he sees me as acquisitively disciplined as I say I think I have no self-control what's so ever.

L: Maybe your criteria are very strict?

G: I see myself as one of the most fatalistic people on this planet. I do what ever pleases me, whatever I want. I don't consider that as some sort of self-control.

L: So, in a sense you would say yes, the Diabetes is there, but it did not dramatically impact on who you are?

G: No or what I do.

L: But you did integrate it as part of your life?

G: I have too. You know it can't sit out there like some wart, you know it is part of it, but I don't believe in sitting down moaning one's fate. I just get on with it, I am too busy, and I've got too much to do at the same time I am not saying that I am too busy and therefore ignoring it, because if I ignored it I would not been able to do the things that I've got to do.

L: If I listen to you and I do not know the history that you well controlled, it may sound that you did not integrate it ...

G: ...because I ignored it so much?

L: That is the feeling that may come out. Here you are ten years later and you still won't share that in a conversation.

G: No, well there are lots of things that I don't share in conversation that is just one of them.

L: But that is your priority and if you do not want to share that is fine, but ...

G: Why should anyone know about it? I mean no one is interested. Do you sit and discuss your medical history with people?

L: No, I don't. I just deal with what ever I have to.

G: Exactly. Nobody sits at a dinner table and start telling about, well some people tell about how they had their baby, enough to turn my stomach, but I would never discuss my

medical any thing with anybody, because it is so irrelevant. I talk about this or that or my horse or what ever, but I don't discuss sort of my personal things.

L: But even if you say that, you did integrate it?

G: I have to. Absolutely have to, it is part of my life an if I don't take note of it, I can't ride my horse, I can't go to gym, I can't...

L: So there are consequences?

G: Off cause and I am aware of those consequences and as I say, I don't want to get them, so it is up to me not to let it happen. It is not up to anybody else as I said earlier nobody else can take charge of this, I have to. Dr. D can help me and Dr. D can advise me and Dr. D can tell me the latest things that are happening, but at the end of the day I go home and I have to deal with it. So, I do and you know it becomes, just becomes like brushing your teeth. You know you get up in the morning and you brush your teeth. So it just becomes a routine, part of your daily routine. And the longer it goes on the better you get at it, because as I say I know that I don't eat this and I don't eat that and I... if I go to some dinner party, that is another reason I don't tell, because they may go – oh, and I am vegetarian as well and they really go – oh my God, she is a vegetarian, what are we going to give her to eat. What if they knew I am diabetic too? They will have heart failure. So I think it is enough that I am vegetarian. So I go to people's houses and what ever they put in front of me, as long if it is not flesh, I eat it and the pudding I will probably have a few spoons full and say I am full thank you very much. But, ja I don't say a word, because people get in a flap about it.

L: And in the early months. Is this a skill you developed or is it something that just happened?

G: No, Dr. D put me on the straight and narrow, because these other doctors and I spoke too many, did not have a clue, they did not have a clue and I knew this was all wrong, I just knew that what they were telling me was not working and that there was some other way. I did not know what it was.

L: Did you say that to them?

G: Oh, no. The medical profession, you know what they like, they God.

L: Tell me...

G: You know they think that they know every thing. And in fact they know absolutely nothing half the time. They – I have no respect for them. And they were saying absolutely rubbish; the one guy did not even know about night time insulin, he was telling me to take 19 units of insulin when I go to bed at night. I can kill you! And I just knew this was all wrong. Just common sense.

L: Was that an instinct thing?

G: Yes, common sense. It was not right, this was not right, so I am not getting any results from this. When Dr. D got hold of me or I got hold of Dr. D, he said, “oh no, this is what you do – you have a night time insulin, you have a day time insulin, the night time one you have to experiment with to see what’s going to suit you and the day time one, again you have to experiment with it once you have eaten.” He would, he said... I said I am going to test my blood sugar after my meals not before, because what can happen before, you take the insulin and then for some or other reason your food is delayed and the next minute you dip and then you in trouble, I thought that is crazy, why do that, then you stressing yourself up, because now you have taken and where is your food, you at a restaurant, you at some one house... So I thought no, that is crazy. So I always take my blood sugar after I have eaten or if I am about to sit down, maybe I will go and take a bit of insulin, but I don’t, I have my meal, then I take my blood sugar an then I take my insulin. So I am dealing with the event afterwards and for me that works, because you don’t end up sitting there with a white face and God knows what at a dinner table or in a restaurant. And he said to me you have to trial and error it yourself and see what works for you and that is what I did and it was not that hard. You know that, it just took a bit of common sense. It is not, you don’t have to be a brain surgeon or a what ever. It is a little common sense and one starts slowly, you don’t take a huge amount, just a little bit and yes over a period months I sort of saw what the amount of insulin I needed to the amount of food I have, what the results were. It was not good enough or I was fine or it was a little bit too much or what ever...

L: Do you think that it works so well, because Dr. D was there as a support system, but he in a sense gave the control and the responsibly to you and trusted you enough to figure it out for yourself?

G: I would say that is exactly why. The thing is I demand that sort of thing, because I consider myself with bags of common sense and so I don't like people telling me what to do. I like people to advise me and I like people to give me information, I have to have information so that I can make some sort of informed choice and I used to phone Derrick quite a lot and say to him and I am very in tune with my own body and I said this has happened or that had happened, why. And he would say this and this. I can't give an example it is too long ago. And he would say it could be this and it could be that or it is definitely this, now you must try that and because I am aware of what I am doing and where I am I could give him instances and then he could give the answers or...

L: So there was a collaborative relationship, where the typical medical relationship is an authority figure that tells you what to do.

G: That tells you what to do. You see because I know my body better than the man across the desk.

L: So you are telling me in a sense you the expert.

G: On my own body, yes.

L: Diabetes for you, you the expert?

G: Yes.

L: And that is where the friction came probably with the other doctors.

G: Yes, they were insisting that I need to do this and I need to do that – I don't do insist work.

L: You could voice this?

G: No I did not voice it to them, I just left. Because I don't bother to get in confrontations with... Some one got to tell me something in my mind it is got to make sense, if it does not make sense I will question it and if it still can't make sense I won't do it. I came here and what you told me, made sense as far as eating are concerned, I am seeing the results, except for this weekend and therefore I do it, but if I come here and you start telling me all sorts of things and I thought I do not know about this I would have given it a go, with a lot of sort of not necessarily negativity, but skepticism, yes. I would have given it a go, but I would be thinking, I do not know about this. So people have got to motivate for me, because I question what they tell me. If I don't think it sound right, I will question it. But it does not mean I will just not say no outright, but I will be skeptical about it. And the

things Dr. D had said to me made sense and the fact that Dr. D gave me plenty of room for me to move, it was not straight and narrow. That why I tell you I don't see myself as very controlled, because I have to have space this size, so that I can maneuver and find my way around, my own ideas on the matter and so on, but I will go to people and get loads of loads of information from all sorts of people on that subject and then I will and then sift it for myself and make my own mind up about it and if the mind is not made up hard and fast ever, I am always open to ideas and I am always open to suggestions, but they got to make sense to me and Dr. D made absolute sense. I don't speak to GP's or even the specialists about Diabetes because most of them don't have a clue, so you know, as I said he ... you know these guys all leave the country... and I will be devastated, because he is my rock, he really knows what he is talking about and he, I think also he, because he runs the clinic at University A and I think he deals with so many and he has seen so much, you know, but ja, the one thing I cannot understand is why people do not deal with it – the lady outside here was telling me about her husband with Type II Diabetes, I would hate to be a Type II diabetic... It is a different story, those pills does not work...

L: Why, most people fear insulin? That is the thing what the doctors will say if you not compliant we will have to consider insulin.

G: You see the insulin is so easy to deal with. OK, it involves injections and pricking your finger it is some sort of a pain, but it is so much more precise, those tablets are ridiculous, you know every body I know that is a Type II diabetic, they all die young, they all end up with major kidney problems and so on, because those tablets are really not good enough.

L: Do you feel with insulin you know exactly what you putting in?

G: Exactly.

L: And that gives you control...

G: Dr. D suggested to me that I try the disposable cartridges; well they work in two units at a time, what if I only want one unit, and I don't want two. I said to him I am not using that, because, you know, I said no, I am not using it, because they are not precise enough for me. I liked to have these things in half units, because, you know then you can get it right down to almost perfection, but he is a very approachable man, he is a very open

man, he is a I saw him in a restaurant the one day, with a pudding in front of me, I was not embarrassed, I enjoyed every mouth full, because he is happy to go with you as long as you are giving him the results and he is been nagging me about my weight and that is why I came here, so I say to myself, yes the weight is becoming an issue, I don't accept having children, being over forty or any of those things as an excuse for weight. Any excuse for weight is what you put down your throat, so I thought I must do something about this, but you know, he calls me a 'blob' , but I got sick of been called a 'blob' so I am going to do something about it, I am not going to go... I am a 'blob' and become a bigger 'blob', so no, take the bull by the horns and do something about it. So, I don't I see this as a unfortunate thing, I don't see it negatively, I see it sort of as a slight irritation, but if I am going to have a disease this is the one I rather have above all the other diseases, this one is fine, I am happy with this one.

L: And any bad experiences, when things really went wrong?

G: No. I have never, I had a few bad lows, but nothing, I never had anything, touch wood, but again, surely, I said to Dr. D the one day, I said I hope you are not lying to me, I hope that I am doing all this right and I am getting the results, If something goes wrong with my kidneys, I swear to God, I will find you- because you see, I had, I am trusting him that he is telling me the truth and I think that could be quite a devastation for me if I found out he was actually lying...

L: Or if you have been doing everything right and...

G: And something still went wrong...

L: ... doing everything by the book and you end up with....

G: no leg!

L: ... or a kidney problem?

G: Ja, ja, I would be very upset about that.

L: Because that will mean that the input you have put in ... that will take the control away?

G: Ja, that will mean I have wasted my time. I could have been a fat "blob" and had this and had that and not look after myself and not looked after myself, because that was going to be the result anyway and he promised me, he said Gloria, if you do what I am telling you it is not going to happen. And I said, Dr. D, I hope so, because, you know, I

would feel very agreed if in fact this was always going to be the result, no matter which way I approached it. Do you know what I mean? And he has promised me that it is not going to be so. Yes at some point I am going to die and I am sure Diabetes has shortened my life, but what he hell when I am dead I am dead. It could be a truck; it could be a heart attack, which I would have anyway...

L: But the quality is important?

G: The quality is important. If I am going to be hit by a truck or a car at least I would look good when I died. You know what I mean.

L: I think that is important, because in the literature with chronic illness there is a lot on identity. That if some one get a chronic illness that may affect who that person are – so if you are a very active person and suddenly something happens that you can not be that... That is huge for most people, now what I hear from you is that it did not affect your identity, you are the same. You can not tell me this was life before Diabetes and this is life after Diabetes. It is not that significant for you.

G: It is a heavier handbag that is all.

L: It is a straight line, it is not this significant, that you had to integrate different identities, because it is like men that had huge heart attacks after that or they have a bypass...

G: ... and they cripples...

L:...and they not entirely the person they used to be and they struggle with that, because they can not do the things that they used to do and that is huge for a lot of people...

G:...I am sure it is.

L:... and you feel it is ten twelve years along the line and there is nothing like that, you have the same identity you had before diagnosis; but if that changes, if something happens and you have to go for dialysis, whatever – that would be...

G: I would not, I would just take a huge overdose and that would be that. I made that decision a long time ago, if something like that happens, I would just end it, because I don't see any point, because then the end is near, so to speak and what sort of quality of life you've got –ziltz, so I would not deal with that. And that would be my personal choice and you know, religion may come in to it, this and that, but that would be my personal choice. That is what I will do.

L: But up to this point it did not affect you that significantly?

G: Nothing, nothing like that, as I say I will feel very let down, but the thing is I have got to, you know the one thing I do have to understand as I said earlier, my life will be shortened because of Diabetes and I do have to understand that possibly as one gets older the diabetic influence on the body might cause a problem.

L: I think in terms of organs, yes.

G: Ja, because it is stress.

L: It may be a stress for the heart, for the kidney, basically all the organs, but what I can say from what I have read from the studies that they have done over long periods of time that if your blood sugar are at those values that Dr. D is looking at, that there is a significant lowering in complications. That is scientifically proofed, but like all things in life it is not guaranteed?

G: No. And he said to me that he has people in their seventies that have been diabetic for thirty, forty years and they must have seen huge changes in that time. He said absolutely fine, look they are going to die, they might have a heart attack or a stroke that might have been diabetic related or not. You know, it is not something I am going to worry about at this point. I do not look further then the next three hours, quite honestly, because you know, why bother, why worry about ten years time, I might be dead in five years time. I don't think about things like that, I think if there has been ever a significant change if you want to put it that way, is that perhaps – I have never been someone who cross bridges before I have got to them or sort of thought years in advance, but I definitely don't now, because I have to live each day as I go along, I take each day, whether it is with my insulin or my food or whatever, a day at a time. If I get through this day, I will worry about tomorrow, so...

L: Do you think Diabetes got anything to do with the way of thinking?

G: I think, possibly as I say I have never been someone who is worried about the future. I live in the present, very much, I have never live in the past, either, I don't take have a camera, for example. I don't take pictures, because I do not believe in looking at what happened then, it is all here, so I am a very present focused person, but ja, possibly this make it more so.

L: Maybe highlighted it?

G: Highlighted it.

L: Anything else that you would like to add?

G: No, I wish that everybody just get their act together, those diabetics out there, because they don't need to run around feeling sorry for themselves, do they? Very sad, indeed. And now I am not going on promotional chats and talks and tours... Nobody will pay to come and listen to me.

L: How was it to talk about it? You thought you will have very little to say.

G: Ja, I suppose time flies, is it not? I did not realise, well you prompted me.

L: OK, we may end it here, thank you.

APPENDIX (III) Interviews with the Professionals

Interview with Dr. P

L: I think where I will start is if you have to define your role as a doctor; what will that be?

Dr. P: That is a huge question?

L: I know ...

Dr. P: Obviously you are there to take care of the patient's needs and when I say the patient's needs, I am talking about their physical needs, obviously I can not take care of their spiritual needs, but I need to respect possibly what their spiritual needs are, you know everybody has got different spiritual needs and respect those and often to a great extend, a very great extend is their emotional needs. So I think you are there to look after those things, physical, spiritual and emotional needs.

L: Do you think the way that medical professionals are trained, do you think we are fully equipped for that?

Dr. P: No. Definitely not, not when I trained, that is for sure.

L: Why do you say that?

Dr. P: They only train you in the actual disease or disease process that you are dealing with.

L: So you are dealing with the illness and not the person...

Dr. P: Not the person, you deal with the illness or that is what they teach you, but they forget to teach you that, that illness is owned by somebody, who has got their own life and their own emotions and their own needs and their own other problems.

L: And I mean you have been practicing, how long now?

Dr. P: Twenty, twenty five.

L: Do you think your role changed from where you started out and where you are today?

Dr. P: Oh, Ja.

L: In what way?

Dr. P: I think you just grow with the experiences, you know. And you as a person also get that much older and your life experiences teach you, you know.

L: So you get sort of equipped through the process?

Dr. P: I think so, ja. I mean look some doctors don't like the process, so they bomb out and they leave, it is too much.

L: Can you explain that?

Dr. P: I think some doctors found that they don't like if they feel a patient is leaning on them emotionally. No you not there to solve a patient's emotional needs, but I think you have to be there, when they sad, when they frightened, when they feel helpless, you have to be there, its part of the treatment and treatment does not necessarily mean healing.

L: Do you think it is different for acute illness vs. chronic illness.

Dr. P: Yes, I do.

L: Do you think we need a different approach?

Dr. P: I think that a lot of illness anyway in medicine is, either you can manage it, you can't necessarily cure it, if someone got a boil you can cure it, you know, I mean, there is certain diseases you can manage, like Hypertension and Diabetes and then there is some diseases that you will manage until the end of that person's life, because that disease you can't even control necessarily. So you going to look at like a boil and a hypertension and a terminal illness differently and one person may have all three those things.

L: How do you cope with that if you ... to put it differently, what are the expectations of patients if they come to you with a chronic illness? Do you think they realise it is not curable? What do you think they want from you?

Dr. P: I think often they will know it is not curable, they need your support, they need some one they can talk to in that they can get explanations for things, like I am just thinking of a patient now, I am sure she has a melanoma, I am sure she has, she is very frightened of this diagnoses, but I mean the diagnoses has not even been made yet.

L: And the process, I mean you have diagnosed a lot of people...

Dr. P: Ja, and often it is a shock you know, but often it is not such a shock for some people, for example if somebody comes here with a lump in their breast, they already have thought the worst...

L: They may already have gone through that process till they walked into this room...

Dr. P: ... because they tell themselves what if I have got x y or z , but you know, you take something like breast Cancer, I mean it is a shock when you got told yes you have a lump in your breast and it could be Cancer, then you go and have a biopsy and yes and it is Cancer, but you know the reality of the whole process only starts to sink in when you start with your chemo, then your hair starts falling out and now you have been six months on chemo, you had your partial mastectomy or mastectomy, your friends all think –oh well six months down the line, she is fine, but mean while it is different things you are facing all the time and once you had your chemo, maybe you have to go on radiation and then you sit and you wait and every six months you have to say let me go and hear if I am still in remission or not.

L: So it is life long, it is never cured ...

Dr. P: Even if you are in remission, you always go back to make sure you are still in remission, because maybe you are not.

L: There is a constant reminder ...

Dr. P: ... that stills hangs over your head.

L: So if you diagnosed do you think it is sometimes a relief for people in the sense now they know what is wrong?

Dr. P: Yes, I do think so, but certain illnesses for example if you tell someone they are HIV positive ...

L: What is your experience with that, how do people react?

Dr. P: Shock.

L: Can you see it?

Dr. P: Ja...

L: And denial?

Dr. P: Depends on the kind of person you dealing with, yes denial, like I had one patient – he was very angry with me because he was diagnosed HIV positive and now he is going to church, he is praying everyday and he is livid, because he is still HIV positive. But he is taking it out on me.

L: And how does that make you feel?

Dr. P: Well, I spoke to him and said you might be praying for a miracle, but you cannot tell God what you miracle must be. God decides what that miracle must be.

L: So, you basically worked with what he as coming with, from a religious point of view?

Dr. P: Ja, you have to stick with that. You cannot say to him you are talking a lot of rubbish that if you pray to God your HIV is going to go away. I can't tell him that because he does not believe that, he believes that it will.

L: So you have to work with what their belief system is?

Dr. P: Definitely.

L: And the meaning they have found in their illness. I think that is what I picked up from the interviews, people want to have some sort of reason why this thing has happened to them and they create meaning out of it.

Dr. P: Ja, and they often link it to an event as well.

L: They need to know what has caused it.

Dr. P: And they sometimes punish themselves too, they will say it is because I had an abortion when I was nineteen, now I have Cancer of the breast. God is punishing me.

L: And do the ever discuss that feelings with you...

Dr. P: Ja...

L: And what do you do with that?

Dr. P: No, I don't believe, I say to them, I mean I am not very religious, but I think that is just life, you know. God is not punishing anybody. It is just, it can happen to anybody. It is like why does somebody gets murdered, nobody deserves to get murdered, it just that is what life is about. Unfair things happen to good people. That is life.

L: Although people tend to want to know, they would like to have a reason.

Dr. P: But like I say to them, we don't know. It is like someone, I had a patient I looked after, and he has been bedridden for the last 15 years with MS. I have looked after him in Haven's. He can't sit by himself, he can eat sloppy sort of food, his got a catheter, all he can do is lie in his bed and watch TV, he can't walk, he can't sit, he can't move, he is like quadriplegic, almost from it. And you know one of the nurses was very upset one day, nursing him and she said to me – what is the meaning of his life, why is he alive, what is the purpose of his life- and I said maybe the purpose of his life is to teach other people compassion. I think we all start questioning what is the meaning of our life, it is pretty simple stuff, maybe his is to teach others compassion.

L: Do you think if you think of him that he has got some meaning – that his life is in a way meaningful?

Dr. P: He never complains, but I never have brought that topic up with him, I think his brain functioning is at a point where he cannot have a conversation that long.

L: And I know you work with very hard things, you do the HIV, the hard medical stuff and what does that do to you?

Dr. P: I give you one example, Linde hey, this weekend I saw a young girl, 24, white girl, pregnant, 34 weeks pregnant, 35 weeks about, she came in here in labor, never been to this clinic before, no she has been, I am sorry, she 's been once before and two weeks ago she was gang raped by two blacks – quarter to nine in the morning, she was walking to the shops, she begged them not to rape her, they tied her up to a tree and they raped her, they only left when the one stuck his fingers in her mouth and she bit as hard as she could. So she is on anti-retroviral and she delivered a dead baby, intra uterine death which probably occurred at the time of the rape. How does she deal with that? Because although she had a dead baby and the pregnancy finished, that is in a way a chronic psychiatric thing that is going to plague her.

L: It is going to affect her...

Dr. P: And God forbid she becomes HIV positive through it all.

L: And you how do deal with stuff like that? The hard stuff?

Dr. P: You do visualise it, quite a bit. I sometimes write things down, like things that I found a little bit hardcore on my soul, I read quite a bit, I try and do nice things, you know...

L: For yourself?

Dr. P: Ja.

L: Ever had burnout, ever felt it was too much, these things that you cannot explain to people, they do not become better, ever felt that it is too much?

Dr. P: No, not really illness so much, I don't get burnout so much from that, because we all actually got it down and you cannot cure everybody and you cannot make it always better.

L: And you have accepted that?

Dr. P: Yeah.

L: And when you were starting out?

Dr. P: Oh, I tell you why I have accepted it, because I got *Stephalloc...*, start again *Staphylococcus* septicemia myself in 1989 and I was in the clinic for three weeks and I was very close to death, I lost 15kg, I had two laporotomies, they called my parents from Cape Town and I had a near death experience. You know, people think that is nonsense it's the omni..., but it is not it is definitely not. And that is a life changing experience, well it was for me and I think for everybody who has experience that, it is a life changing experience and for myself I don't fear death, I don't feel uncomfortable talking about death, I don't feel uncomfortable asking somebody how they feel about it.

L: Because you said it is part of life?

Dr. P: Yeah. It is part of the cycle.

L: Do you think after that experience, you worked differently?

Dr. P: Yes.

L: In what way?

Dr. P: It is hard to put in words, you know. Because I don't think that death per say is a frightening experience I think what you fear is how we going to die. Will we have pain, will we be tortured, you know, that is what we fear, but what is on the other side, nobody really knows. I mean the churches may tell you if you believe in God then you may ... they don't know that either, they don't, but if that comfort somebody, that's fine.

L: Then you go with it?

Dr. P: Ja, Off cause. But I don't believe that you get punished for things that you have done in your life and that is why you get ill.

L: Why you get Cancer and all this terrible things....

Dr. P: No, it is just, it can happen to anybody. We all going to get something. If you take a hundred years ago I would have been dead by now, I am sure. Most people ...

L: I was born with Hirsprungs, I would not be able to sit here today.

Dr. P: Oh, Really...

L: So, my son as well and if you think years ago that kind of technology was not available.

Dr. P: I think what also played a big role in my life is when I was ten I got Nephrotic Syndrome and I was off school for six months and I was on medication till I was twenty one.

L: Do you think that experience gave you more empathy with people?

Dr. P: I do think so.

L: ... that you do know what they are talking about?

Dr. P: You know, I know what it feels like to have to, I remember going to school every morning my brother had to run in with a sample of urine to the doctor and in those days they did not have a urine dipstick, they burnt it with a Bunsen burner and I can remember looking at my urine, I was ten years old and suddenly over the Bunsen burner – it clotted like egg white, solid you could take it out of the test tube and those kind of things I have not ever forgotten, you know. I think your life experiences mold you, I don't know some people who may have been spoiled and have never had any hardships themselves, perhaps don't, they don't understand because they have never been there. I mean I have grown up in an alcoholic home, I will never lose it with someone that is an alcoholic, you know. I try to understand where they are coming from. Drug addicts I am not very good with, I probably should feel the same way, but somehow ...

L: I think we all have our blind spots...

Dr. P: I find that a lot of them, they quite deceitful people, but I suppose everybody is coming from somewhere for a reason.

L: So you would say those experiences...

Dr. P: They must have had an affect, they must have...

L: That shaped you in the kind of doctor that you are. The feeling that I have got from patients is that they want to go with this disease with someone, they want an authority figure in their life, like a doctor, sort of an expert that can guide them, but they also want their feelings and their experiences acknowledged.

Dr. P: You know that is one thing that I think a lot of the specialists don't do. Like for example one of my HIV patients, I mean now he's got rectal Cancer, rectal carcinoma and I mean his got massive metastasis in his liver he is on *Deorodisac*, I am not going to tell him to stop his HIV medication, because for him that means, that is it, he is finished.

L: A sign of no hope?

Dr. P: Yes, so let him take his pills, I mean if he forgets to take them, it does not matter, but I rather not say to him, don't take your HIV medicine, you do not need it, because you are terminally ill. He looks terrible, he had like a shunt thing put into the rectum that it can bypass the tumor and he is positive again, but when he was diagnosed with HIV, when I diagnosed him, first he came with Herpes and he has been a bit of a naughty boy in his life, I love him to bits, he is a real character, he is in his sixties, but I just said to him you cannot walk this path alone, this HIV path alone. This was like nine, eight years ago, I said you cannot and I said you and your wife has slept in separate rooms for firth teen years, she does not need to know how you got it, because he got it from a black prostitute and I concocted some story that he helped some guy that fell of a crane at his work.. You know what he is a hero in her eyes; the family is supportive of him. Do they really need to know, how he got it? No, I don't believe that they do. I know it is a bit off a lie, but they don't, they don't need to know that for them, they don't need to know he is sleeping with black prostitutes and he is not doing it any more and he needs their support. So I told a lie, because you know what sometimes you have to. So what difference does it make? If he told them he got it from a black guy that fell of a crane or he slept with a black prostitute it's got different implications, hey.

L: For his wife, definitely, ja.

Dr. P: She will be peeved of with him and it creates a whole another emotional roller coaster, which none of them need, none of them need that.

L: And that is the part I mean you did not do anything 'medical' there – you looked at the family and the system and decided what would be the best for this guy and his system.

Dr. P: Absolutely. It is a bit of a lie, but I don't believe it was the wrong thing. And also, the other day I saw a young girl who was involved in the Tsunami in Puket and she is quite traumatised and she really, she has got post traumatic stress disorder and she saw a GP that just said you are depressed and you have got to have an anti-depressant, but did not talk to her at all. What I have said to her is that what she is feeling is so normal. And I could relate to that because I had post traumatic stress before myself. I am telling you all my secrets here.

L: It will be confidential.

Dr. P: You know, my brother- in- law was murdered, I worked as a district surgeon for two years, I have worked for the child protection unit, with sexually abused children for nine years and it was the weirdest thing when I had that robbery, it was four years ago, it freaked me out, hey. They have tried to kill my dogs and threatened my life and although nothing happened to me, all these other stuff just came flooding back. I understand where she is at. I could say to her you are feeling this and this and she said how you know that.

L: And she probably could pick up that you sincere in that.

Dr. P: I did not give her the details of what happened to me, but I said I know where you are coming from, I have been there, a different story to yours, but I have been there.

And I said you are normal, don't let your family tell you to pull yourself together, it will come right. It will, it will take time, but time heals. No, you have to be a bit of a psychologist, I think. And you have to be careful not to be condemning; sometimes you can't help it though in your head, you know.

L: Do you think you ever show that? I mean you do get patients that just piss you off?

They just rub something and it is very difficult to keep that...

Dr. P: I am very outspoken and everybody knows that. Like for example when I was a district surgeon, they say to you don't be judgmental. Well, I mean I saw this black woman, she was tied spread eagle to the stair case, she was a domestic worker, spread eagle to the stair case and gang raped by four guys and she kept saying they are waiting for the madam and they are going to do it to the madam as well. Fortunately the neighbour kind of smelt a rat and he phoned the security company and the police and they caught two of them and they shot two of them. So when they caught them they brought those two guys and her to me. So I had to examine her first and then examine the perpetrators and I said to the guy, he pretended he could not understand any English. So I examined her and I was traumatised because of what have happened to her. You can't look and do that kind of work and feel nothing, well I suppose some people do, but I don't. And he pretended he could not understand English, he pretended he could not understand Afrikaans...

L: And you lost it a bit with him...

Dr. P: Ja, I lost it ... you supposed to comb the pubic hair... I thought your swine, I took a forceps and I clammed about 50 hairs and I just went I took great pleasure in that.

L: So you felt better?

Dr. P: Yes!

L: So we are all human?

Dr. P: Ja, of cause, you do get days where you feel –oh God what are you telling me. Hypochondriacs, I am not good with. I am not; I am not tolerant to them.

L: Will you straight off tell them you are talking a lot of rubbish here?

Dr. P: OK, I will give you one example.

L: Or do you play with it?

Dr. P: No, I am not good with playing with it to much. I am not rude, but I am firm. Like here, I will read you this list. This is my, this is a winner. Now this guy arrives to see me. Seen me a number of times for all sorts off nonsense complaints. This time he arrives with a list and his hair is like this as he's been lying down all the time, you know that kind of knotted look and he is young, only in his forties. These are his complaints in one consultation; he's got weakness, he has had nausea for two weeks, every morning, but it is not like that if he sleeps on his side, he's got lose skin on his gums, he's got red eyes with yellow giblets in them, I don't know what he means by that, but he has got that for a long time, years, so it can't be an infection, puss in his tonsils which he had for ten years, ear infections, especially on the right, he also had that for ten years, he has a left sided post nasal drip for ten years, mouth ulcers which he thinks are herpes, dry skin in his right nostril, which peels for ten years, he's got reflux and colon uneasiness, he's got flem in his larynx, he thinks he's got prostatitis for at least two years, he's got urine retention, he's got an ache in his left arm on occasions. Do I think it is stress? This was my best, cold feet for two hours after a bowel movement, burning eyes; he thinks he is not fighting a virus which he probably got in town Q, he is sure he's got an ulcer and his appetite is gone everyday until three pm. Now you can't go with this, you can't go with this!

L: So what did you do?

Dr. P: So I said to him please give me this list, we will do just a general check up on you, just briefly to go through these, some of this I said it is not medical, like cold feet after a bowel movement, I mean that is my best. I said that is not medical, I just deleted it of the thing, I just did not go there. You can't buy into that, you will drive yourself of the edge; you won't be able to do this job. I just said to him that is not a medical problem. The

other things I lumped together, this left sided drip and right sided peeling nose, I said you go to an ENT, I don't have the equipment to look there, I have only have a light. No, no, you can't buy into this kind of stuff, you will go mad.

L: Do you get that often?

Dr. P: No, the hypochondriacs do not like me.

L: Because you straight forward.

Dr. P: They don't like me. Because I will say to them that is not a medical problem, there is no such thing. Like these people that want to have yuppie flu, I just say to them look there is two schools of thought. One school of thought feels that there is such a thing and one school of thought feels that there is not. And I belong to the school of thought that believes that there is not.

L: So you straight forward?

Dr. P: Ja, they don't like it. They won't come back to me. I don't want someone like that, I don't want them, I have enough patients. I am here to deal with people that are really sick or needs me, you know. Like someone always phoning to threaten to committing suicide, that was one of R's patient's. He was on leave, I said to reception to put her on to me. I said how you are going to do it. No, she has not thought. Ag, please....

L: I suppose that also comes with experience.

Dr. P: R used to get in his car and go to her house. Completely manipulative.

L: So what you are telling me you also have boundaries?

Dr. P: Definitely.

L: There are boundaries that you will put up and say with this I will deal and this I won't

Dr. P: No.

L: And you will communicate that?

Dr. P I won't be rude, but I will be very straight forward. It is like somebody came to my house one night, somebody that lives in my complex, a patient of mine and I always felt that he tried to come on to me, but I could never put it on anything. He arrives at my house one night at eleven 'o clock; he has had a headache for two days.... I have been out for a few drinks with the girls, you see and I gave it to him, oh boy. I said don't you dare, don't you dare to come here, I said this is my haven and my privacy, you make an appointment at my practice or if you feel it is so bad now, you go to casualty. I said don't

you dare to ever come here again. Now he is too scared to even look at me. If I drive past he looks down. Yes, so maybe I am a bit harsh from that point of view, but I promised you if someone really needs me, I will be there a thousand percent of the way. But don't rub me up the wrong way with nonsense like that.

L: So it is about boundaries. What will happen if you don't have boundaries?

Dr. P: They will devour you. They will devour you.

L: I think expectations from patients are high and they may need all the time.

Dr. P: And sometimes they want to feed of you. You can't allow that.

L: How do you deal with that?

Dr. P: Well, I feel it. I know when someone is feeding of me. I know when they feeding of me and I will put a stop to it.

L: What about patients, especially in chronic illness that is just incontinent? Your diabetic that just pick up weight and do what they want...

Dr. P: Oh look with those... I just say to them, like say someone that is hypertensive and they don't take their pills and they overweight and they smoke... I just say to them, look this is what you need, you have hypertension, it is not curable it is only controllable and really at the end of the day it is up to you, I am not your policeman, if you don't mind having a stroke and wetting yourself and stuff, that is fine it is up to you. If that is what you don't mind, you must do it. I use a bit of fear tactics with some of those. And if they don't want to listen, you know what...

L: It is not your responsibility?

Dr. P: No, I am not their policeman. I can say to them. This is what your problem is, you can't cure it with one month's of tablets, you need to change your life style and take your medication. If they don't want to do that, well I can't, I mean, that's it, I am not their policeman. And I am a bit harsh when I say to them, fine as long as you fully understand that if you do have a stroke that is what your choice is. And if you can't speak one day and you need to be in frail care with Moducare nappies and dribbling and drooling, that is up to you. That is your choice if that is what you don't mind.

L: And then are they compliant?

Dr. P: Sometimes they are and sometimes they don't come back to me. And sometimes they are just the same. They frightened for a week or two and then they just go back to

their old ways. I think most of the time what doctors need to realise, most things you can't cure them, most things they are not going to listen to you, they not. I mean you know that with diets.

L: I know, that is why I am looking at this. You know how we are trained, this is the disease and this is the treatment and this is the advise you give, stop. And half the time you miss the process what the patient is going through, you are unaware.

Dr. P: I know, like eating things, I mean the problems I here, they not saying I bloody will eat chocolate cake because I want to, it is a far deeper thing than that. It is like depression as well you know.

L: And the way that we used to be trained, maybe it is different is not looking at that at all?

Dr. P: The human mind is terribly complicated, hey. And often diseases like adolescence with Diabetes, they bloody cross that they have this disease.

L: They are angry.

Dr. P: Yes. And people with Cancer too. Why me, why me?

L: They may go through a whole process...

Dr. P: And they sometimes get angry with you as the doctor.

L: Maybe because you represent what is happening to them?

Dr. P: But I understand that it is not about you. It is not about me.

L: But that takes experience, I think.

Dr. P: Ja, it is not about you, but sometimes you have to draw the line if people are really rude I will actually ask them to please go and see someone else. Because you not obliged to take that kind of abuse, you not obliged to, I mean with in reason, but you not obliged to put up with people that are damn abusive.

L: Anything else you would like to add?

Dr. P: Maybe we must just have a second talk.

L: Ja I think the things that we touch on is some things from the literature, like dealing with the person and not only with the illness, boundaries with patients those kind of things...

Dr. P: Oh, we have to have that, that is why some people burnout in medicine. I don't think I ever really had burnout.

L: Although you work with the hard stuff? So you must have a way of dealing with it?

Dr. P: Well, look I mean a lot of the sexual abuse stuff I stopped doing that now. I still lecture for them. I gave a lecture to the medical students on rape and I got very good feedback. They had three different people doing that rape lecture in the last three years and every time and I have seen their lectures and I can see why did not work. And when you read those lectures, those are people that have never dealt with a rape victim, you can see it. You can only really talk from your heart, I think and that is from your own life experiences, like what I have said about post traumatic stress and being ill as a child. I was put on huge dosages of cortisone, I went back to school after six months and the teacher said to me come here, are you the new girl, what is your name.

L: Did it change how you had looked?

Dr. P: Yes, I was on big doses of steroids. Huge and the teacher did not know who I was, that freaked me out, hey. That really freaked me out.

L: Loss of identity?

Dr. P: Yes, totally.

L: Last question, why do you think we choose these professions?

Dr. P: I think a lot of doctors come from situations in their childhood where they become the caregivers or they are the rescuers.

L: And they continue that as professionals?

Dr. P: Yes and I think that is where I come from.to a certain extent, because I was always rescuing my mother and maybe what influenced me more was my own illness, you know. But, yes I was in rescue mode from when I was very young.

L: And you actually are still doing that in a sense?

Dr. P: Yes I am.

L: But maybe that is who you are?

Dr. P: Maybe I am a healer, I think. I hope to think, I hope I can help some of the people, some of the time, but that is all you can hope for. But I think a lot of doctors do come from rescue mode that is why they are here. Lot of people in the healing, helping professions.

L: I saw it with the psychology. Sometimes people think you are wonderful and they tell you that....

Dr. P: You know and you sometimes need that. We all need stroking.

L: And sometimes you have to be careful to figure out why you doing this and who is the important person here. Sort of the person opposite you or you. Whose needs are being met?

Dr. P: You know that is exactly what I was... I was so angry with this doctor at this care facility. Like with these people, Stefan Smith, his name was. He was a fat little tubby American man. Stefan you have to lose weight I used to say. Oh Dr. P if I am fat I know I am fine. Every year he used to go to the States and bring me a pair of jeans, he was a funny little man and I was very fond of him. And they have killed him. Let me tell you nine and a half people out of ten that end up there go out in a body bag. They kill them, I think they do a lot of good work, don't get me wrong, but I think a lot of people that work there, work there for the wrong reasons. They stroking their own ego's and that's all. And you have to careful with that in this profession.

L: I think anything where people come to you, you have power?

Dr. P: And if you feeding you own ego on it ...

L: And if you got the need to be feeded, you may become dangerous...

Dr. P: Very dangerous. I could not agree with you more. It is like I did not work with sexual abused children because I was sexually abused, not at all. I tell you another day how I ended up there, but I was good at it. And I was a mean son of a gun in court, so they liked me, but it did get to a point where I said I can't do this anymore. And they begged me to stay, but I said I can't. For me, I have got to walk away from this, because it was becoming my own trauma, hey. I can't, I could not stop thinking about what some of these kids went through. It was a video playing in my head over and over and over. How it happened; what is must have been like how painful it must have been...

L: So you start living it?

Dr. P: YES, then you have to say this is enough.

L: It is the boundaries again – you have to look after yourself.

Dr. P: And as much as they say you good and they need you... I said thank you I appreciate that, but I can't. It was hard for me to walk away.

L: You don't feel guilty?

Dr. P: Yes, I do. They made me feel guilty and I bought into that guilt. Not anymore, I still help them with lectures and stuff, but I don't want to do the hands on stuff anymore, I don't want to. I always said to them if there is an emergency situation and they need help, I will help them. Yes and it does stroke your ego if you have to lecture prosecutors and the police, but I don't want to anymore. I have to safeguard my own well-being you know.

L: Thank you.

Interview with Sharon

L: I think where I will start, I think just tell me what you do here. What is your role?

S: I will start by saying I had been here for eighteen years and I had various roles in that started as a very junior sister and I did activities with the patients as well, outings and exercises and all that kind of thing. And then about, it must be about eight years ago I was the assistant matron and probably a year later I took over as matron. So my roles have changed, but I tried to maintain my patient contact as far as possible, because it is my first love and why works in a place like this.

L: And why do you work in a place like this?

S: In my nursing training I always preferred medicine to surgery, always preferred the patient care as apposed to the quick in and out and drama of the surgical wards and your patient, your nursing is proper nursing of medical patients. So I did always love it and then when I qualified I did a bit of surgical nursing and found that I definitely preferred this and then after my children were born it was convenient family wise, but also something that I knew I loved. And I came here...

L: And here you are eighteen years later?

S: Ja and love it.

L: Tell me, one of the themes of chronic illness is that it is not curable and the medical model, the way that doctors, dietitians and everybody is basically trained to cure. And the illnesses we deal with today are not always curable. Do you think as a nurse you were always more, you training was in terms of caring and not necessary curing?

S: Yes.

L: And would you say that is different from how you experience other professions, like doctors for example?

S: Yes, I think it is harder for doctors and I also believes it goes back to the training ethic that they should fix people and make them better, where we for instance just to illustrate to you why I feel that way is that I find of the team, the multidisciplinary team nurses are the poorest rehabilitation people, we have to be almost retrained into rehabilitation. Because we taught to do for and you almost feel a bad nurse if you are not doing for the patient, because I think, ja it is easiest, not easiest, but I think it comes more naturally to the nurse to deal with incurable diseases.

L: So the focus is always on care and not necessarily like you say fixing.

S: Yes.

L: So would you say it is easier for a nurse to work with chronic illness than a other health professional that comes from a different way of thinking?

S: Possibly, possibly. I think it is also the individual and what the background of the nurse is, but I think on a whole, ja it would be easier for us.

L: And the kind of illnesses you see here? Let not say the illness you deal with, but the people you deal with?

S: It is actually a wide range. The facility has become very vague in the care that we give, because of the needs in the community, so we have all age groups of people, but certainly 98% of our people come here and that is it, they not going to get better and go home.

L: Would you say in a way it is the end of the road?

S: For the elderly, certainly and most of our elderly people present with multi-pathology, you know, although they might be here for something like Alzheimer's disease or dementia or whatever etiology they also often have the CCF and the physical problems that old age brings with it and the other patients that we care for are head injuries. Those are our two main categories. So no matter what their age they are severe head injuries and that is why they have been institutionalised. So we basically try and offer them some sort of quality of life, for however many years are left to them, as well as with our therapist we do try obviously to enhance and improve quality of life, so we don't give up on the rehab aspect, but we don't get the good prognosis people, obviously because they would not need to be institutionalised. So we work with the severe head injuries.

L: How does this impact on you?

S: It does, it does, it is interesting that... I think all the health professions have become a lot more aware in later years of our selves in this picture and what it actually does to you. So for years I actually did not realise that sometimes my emotional state possibly could relate to the work that I do. But over the last few years where there has been more awareness and growth in that area, I think that we fluctuate. The one thing that nurses do have that the other health professions don't have is that we exposed to these people for

much longer, if you know what I mean. We work with them eight to ten to twelve hours a day...

L: It is not a question of like the doctor come in and does his or her thing and then they go. You are constantly confronted with that person's limitations.

S: And unfortunately it is a relationship, well fortunately is built between the nurse and the patient in long-term care. The teaching that I have got as a student that you don't become involved with your patients is extremely difficult to apply to long-term care.

L: Do you still believe in that?

S: No, but I do think there must be an area of self-preservation.

L: Some kind of boundary?

S: Ja, but certainly a relationship builds up and to go back to where I am saying you fluctuate and I think something I observed over the years is fortunately we have different levels at different times and we can support one another, but certainly it does take its toll. I find that I can get terribly tearful at times when one of our patients who we have nursed over a long time goes into a terminal stage and you see them suffering. You see pain and you see distress and you built a relationship with relatives, as well. You come to... I have been nursing people here for fifteen, sixteen years, so you then see the relatives hurt and distress and anguish and unfortunately it does impact and you do ... there are days where I can say I am depressed. There are days when I come to work and see the facility as people who don't come here often, see it. How sad it actually is.

L: Do you think you get blunted for the sadness?

S: I think that we go through periods where your self-preservation kicks in and you see this, but you don't see. You see them as I am coming in to give them medicine, look after them, make sure they are comfortable, make sure all is fine, but you are holding back from letting it... and then for what ever reason you go through patches that you can not do that.

L: So something just triggers...

S: Whatever, whatever your own emotional status is, I suppose and it always amazed me, it is the little things like always in life. We have an Alzheimer's patient just for example that is always rude to us and then one day you will say something to her and she would say thank you so much for everything and I will burst into floods of tears. All these years

later, because you, you hurt, you hurt for these people and I think a different facet for us here is the loss of dignity aspect of mental trauma or mental disease. And it is a fight I constantly pursue with the nursing staff, that we preserve their dignity, because there is loss of dignity in loss of mental function and I found that very, very hurtful not only for the patient, but also the relatives who walk in on these moments where your dad who was never like that is doing something that, that's not really socially acceptable. So, you know it is all those involved and complicated things that do impact on you as a person and I personally believe, when I am asked this question is that the day when it does not hurt me anymore is the day that I know I should leave. So I am really a great and firm believer in love for your fellow man in the nursing career.

L: And what you are saying is, if you don't feel it anymore you can not for fill your role the way you would like to do it.

S: Absolutely.

L: When those times come that you do feel depressed or you feel very emotional. What do you do with that? What do you do with those feelings?

S: That is the interesting thing. Take it out on my children.

L: We all tend to do that hey?

S: I go home and I ... I am actually not bad tempered, I will withdraw, which upsets them and then they question and you almost like those dogs that wants to go to the corner and lick your wounds and that is when I will snap at them and they become quite resentful of that.

L: Are you aware of the process?

S: Yes. I am and I try to explain it to them, cause they are adults now, young adults, but they all still live at home, so they have to put up with me. And I have tried to explain to them that it is not personal and that it is not that I am taking my work home, literally ...

L: You taking the impact home?

S: It is the impact of it and sometimes I just need time out, but I have over the years gone for a bit of counseling here and there, because it would be unfair just to blame the job, because my personal life is been, I have been a single parent for many years and it has been a stressful time.

L: So what you are saying is that no matter how professional we are we all bring a part of our experiences or our life into the working context?

S: And take a bit of your work situation back home again. And I do believe that is just part of the health profession. We are not dealing with the cost of sugar and milk and we are or do I think see very, very sad things. Very distressing things and whether you want it to or not there is that part of you that absorbs it and you need to work through it before you can put it into its right place, I suppose. So, ja I, I try as far as possible now to work through issues so that you don't become a difficult person either to live with or to work with and as I say that's why in the years on and of I have gone see therapists for a little while until I almost sorted it all out in my own head and you feel stronger and you cope better in a given amount of time. I think the two do interchange your personal life and your professional life.

L: And I think what came out just from my experience doing the interviews is that as professionals we are not really so objective. I think maybe we go into it thinking we are objective and we don't have preferences or anything like that, but you always bring yourself into who ever you working with.

S: Your personality, your everything, absolutely.

L: And maybe we should acknowledge that, that in some cases we are subjective and we bring our own stuff in?

S: Definitely, definitely, I found peace in making that acknowledgement...

L: That it is not wrong...

S: No and the only thing I can do about it is what I just said to try and work through whatever emotional crisis there maybe for me within the working environment and the only way you can work through anything is to acknowledge it, is it not? No, you do as I say you build up a fondness for people in chronic care, because it is long-term. And certainly when you have a patient that comes in for terminal care and passes away a week later you can immediately understand why the ones that we nursed for so many years have the impact that it does, it is not just a patient that has died and often your relationship build up with the relatives comes from their need for reassurance and one has to build a relationship with relatives because they need to build a trust in you to be able to

go home at night and sleep. So it has to be, but it is certainly part of the emotional stuff, ja.

L: Because the patient comes from somewhere, it is someone's father or someone's son, so they do come from a certain system.

L: In terms of, what does chronic illness bring out in people? Are there patients that you do not like? Does it happen that some patients just rub you off the wrong way?

S: Oh yes, I think the individual's reaction to chronic illness is individual.

L: What is your experience?

S: Demanding, very demanding ...

L: Do you think they were always demanding people... I think what I am trying to ask is if chronic illness focuses on certain aspects of the personality or enhance ...

S: In physical illness, say it is an Emphysema patient for instance who is now bedridden ... I do believe that possibly a previous personality trait is exacerbated by the disease, but I found that where the mind is alert and the chronic illness is slowly but surely eating away at that person's life, I believe personally that a lot of behavior is born of fear, the fear of the unknown.

L: And it is an unknown path?

S: I found that patients like that, they are demanding, the bell rings every five minutes and they want to, they want somebody close by all the time, but very often when I have monitored it and watched the situation, it is so regularly based on fear – that I would say is pretty real, in a situation like that.

L: You can not predict illness?

S: No, so I would not say that I am convinced yet that it is part of a pre-morbid personality. Sometimes a family would say, my mother was always like that, but other times not. But especially with lung disease, I found this fear, a huge factor of behavior and I often thought, well if I was in a room all on my own and I could not breathe I also become petrified. With our Alzheimer's and dementia's the brain... the personality changes that occur, I tend to get quite uptight with the staff if they say – oh, he was probably always like that... because we don't know that.

L: So you see it as the illness is doing that to the person if they are rude or whatever.

S: Yes, because there is a loss of inhibition in head injuries and in dementia, there is a loss of inhibition and I think all of us have a set of personality traits, which some of us control better than others because our brains are functioning normally. Now you have somebody who has tissue death all over various areas of the brain and the loss of inhibition makes him able to slap you because you did not say nicely will you come and bath with me. And once again I found that correct staff training and adequate communication with the staff you often change those behaviors by how we approach the people, which once again is born of fear. Fear of and this is not fear of the unknown, this is fear in a confused mind that from day to day does not know where they are and sometimes who they are, you know and that is dreadful to feel confused like that. But I would say that we frequently had families say that is always been there, just to a lesser degree. But we had just as often had very distressed relatives, who have said that my husband never swore in front of me and now he is using reams of four letter words when he is angry or whatever. But as far as patients rubbing staff up in the wrong way I think the nurses are more subjected to that than we as supervising staff are, because we don't even spend the hours with the patients that the actual nurses do and I think sometimes I want to give them gold medals for what they endure. For me to be sworn at twice a day, because they had ask me for help is a lot easier to cope with than being the one that has to bath the patient, taking him to the toilet every two hours and feed him...

L: And may take abuse in the process...

S: Yes, often do. But I would be a liar if I said I have not been faced with the real thing of the human factor, I just not like that patient and your professionalism is truly challenged and often it is not because of behavior, it is often like in life, it is just a personality clash, you just do not like their style. And that is once again; who we are comes into it.

L: What I have missed was when you have said it did impact on your children when you withdrew. Was there any guilt from that?

S: Guilt afterwards because I have done it to the kids?

L: I was just thinking that as a mother if you lose it you always feel guilty?

S: Absolutely. Oh, I have mastered the character trade of guilt. Yes, I am an absolute professional.

L: Yes, I just thinking a lot of time we are very cool and collected at work and we have patience with everyone forever and I think in your position especially where you have to deal with staff and patients as well. And maybe when we walk through those doors of our homes you can not do it anymore?

S: Then you right, you go to bed and what is the emotion you close your eyes with – guilt. Absolutely.

L: And the other thing is you said something and I am looking at themes in chronic illness and fear was a significant one. Any other themes from your experience?

S: I definitely witnessed the grieve pattern within the illness long before death occur.

L: Grieving for what they used to be?

S: And that pattern of where you interchange – is it not Kubler-Ross's theory; the process and how it jumps around and you then encounter those different facets of your patient where acceptance can be reached ten times and one can go back to bargaining and guilt and anger and all those things. That is definitely a pattern in the terminal people I have nursed who are mentally alert. Definitely and interestingly we have observed that within the relatives of our mentally ill patients.

L: So they go through the process...

S: Of losing the person they knew. I have come to believe that when a relative of yours dies from Alzheimer's disease, he dies twice, he or she. The person you knew dies and then the physical person. I think it is very stressful on families. So that pattern, definitely it is amazing.

L: I suppose by the time you get here you have very little control over your life in a sense. So would you say that loss of control or the fear of loss of control is a big theme?

S: Yes and loss of choices, it is another facet of the nursing that we do here that I try to discuss a lot to my staff. Give the people choice, the small choices that they have left because there is so little. You know, they have to eat breakfast at half past seven and each meal at what ever and they have to bath in the mornings and not at night because it suits the staff and that kind of thing. So if a patient says to me I don't want to go outside I try very hard to respect those wishes because they have so little choice left. There is dignity in being able to choose what you want and what you don't want.

L: Which you may lose in the process of illness?

S: Definitely.

L: I think my other question was if you have ever experienced burnout?

S: Yes.

L: Can you tell me what had happened?

S: I would not say definite burnout, not definite, but total burnout. I think I have been very fortunate that colleagues and professionals that I have worked with has recognised the symptoms and sort of said to me you heading for trouble maybe you need to take a bit of leave or whatever. I have taken leave a couple of times over the years at a time when I have taken the leave purely just to get some time out. I am not, I don't view myself as depressed person, I am actually normally quite a light hearted kind of person, trying not take myself to seriously, let alone anything else, but I have taken anti-depressants about three times over the years where its just been a course of say six months, it just gets you out of that area that you in and gets you out of that and you seem to cope for a couple of years again until...I think it is once again the theme of nature of my position here and being a single parent, that sometimes the demands are heavy that you don't recognize where you going until you there and then all people you want to be there for you feel you letting them down, so you have to do something. So ja, I have never been burned out that I have to be booked off or anything like that, but certainly not in a good emotional place.

L: And demands, there are demands here and demands at home, I think what I am asking is what about you? What do you do for you?

S: Nothing, all my councilors have asked me that.

L: I am not actually the one to ask that because I have got the same kind of ..., you know I have spoken to a doctor about it there is something about people that choose these professions, we want to rescue or what is that – we want to give and give and never ask.

S: I think it is a personality thing, now I certainly traced back and I am not one that says, oh it was my childhood, but I have traced back my place in the family and I come from a complicated family, we were ten kids, that in my family I needed to be one of the givers for the whole complex thing to work. I needed to be that one that would sleep on the floor rather than to cause a whole big conflict over it.

L: So that was your role?

S: Yes and it is interesting for me and I don't know how relevant this is for you because I can go on and on, but it is interesting for me that in the last time I have done a lot of soul searching that I actually realised that if I did not carry on who I am, which is this person who needs to do for others, that is who I am, I actually would not like myself, anymore. So at this stage, I don't actually think that I want to change. I really don't, I feel I have reached a place in life where I am at peace with

L: So you have accepted your role?

S: Ja.

L: And that is a role that you have chosen yourself?

S: Ja and I have recognised the reasons and I have recognised whether it is good or bad and whether its... and I have recognized that maybe I am like this because of these various things but at the end of the day I prefer in the world that we living I would rather be like I am then like some other personality and I have decided that whether it is spiritually I done a lot of inner searching in all that and I have decided that for my spiritual part this is exactly who I want to be. So I do not have hang-ups because I don't do things for me anymore. The joy I get out of life is caring for people and lying in a hot bath with a candle and a nice glass of wine is not going to do the same for me as knowing that I have done something for my fellow men.

L: So that gives meaning to you?

S: Yes and I have decided I am not going to wrap myself over the knuckles anymore or think I am lacking something.

L: I think maybe guilt can be created because you are not taking time for yourself?

S: Yes and I don't want to and I am not going to add another stress. If I have a day at work where I am given time to actually mean something to somebody that was in need then I had a good day and no amount of self pampering and I hope you understand that this is sincere and not what I think people want to here, Its where I have reached in my life. For a patient here, for me to see that it actually made a difference in an otherwise very sad life – it is all I need to call it a good day. And that is true and that go for my kids too. Oh I am not... I get angry when I get taken advantage of but I want to be there for them and be what I perceive mother to be and that is the one you loaded it all on.

L: Boundaries?

S: Oh I am not good with that. These personality traits never are. But I am better, I am better than I used to be and I believe that is an area that I can work on, not trying to change, but to stop things like burnout and needing anti-depressants and I think if you have good boundaries in place you don't reach those lows in life and I am working very hard on that at the moment and to do it in an assertive way that is not hurtful. To actually say now I had enough and I am not going to give in and I am not going to this anymore. I am not good with it, but I am working on it.

L: I was speaking to a doctor about a patient I think it was here where somebody remarked what the purpose of this patient life was or what is the meaning, that hopelessness is it ever part of your thinking or your experience? And the doctor said she commented that maybe this person must teach us compassion and it is not for us to say what the meaning of other people's lives is.

S: That is such a relevant question...

L: Because maybe somebody from the outside may walk in here and think what is the point...

S: They don't always even think it. That was not the only time that I was asked possibly four or five times over years why we do what we do, because there is no quality of life there is no and once again it has been a road of many little pathways to reach something I found I can live with. At one time I have experience a lot of anger that I actually did not recognise for a long time about why, why does this happen to people, why don't they die? You have this bad accident and you lose half your brain on the road, why, then you find the answer, oh it is the paramedics fault, now blame all the paramedics, then you talk enough to people and they say your son is in a accident tomorrow, you don't know what the end result is going to be – are you going to say leave him to die or are you going to say fight for his life... And that squashed that theory for me. Then I started to think about euthanasia, because with in your worst mental psychiatric or dementia type illness patients often have lucid moments and I had a patient here that have asked me repeatedly on night duty to put a pillow over her head. And you know it sets obviously you try to answer correctly to such a sad request and its sets your thinking going and I actually

become totally against euthanasia within this work because I believe just what you have just said that we don't know the purpose of any of what we see in life. If it is to teach those around about human courage that is just beyond your human capacity to understand you see in chronic illness...

L: I think that is another theme courage, it is amazing with what people can live?

S: It is huge, humbling to be around, so ja I answer people like that there must be a purpose and I don't have the answers and it is not to me to have the answers, but I believe as for long as we are preserving not only human life, but trying to preserve comfort and human dignity that is why there are places like this and this kind of care. I don't have the answers and I don't seek for it anymore, but I do believe in what we do here, very strongly and we don't perform heroics when the final days come, but we also don't play God. We do treat diseases and we try to avoid artificial feeding and that kind of thing depending on the situation, but we don't leave people to starve or die of thirst and relevant to me personally, I think once again its become a more peaceful area for me with the spiritual growth that I have managed to get through brought about possibly a lot by the work that I do. I truly believe that you do let go and let God and you do what ever is humanly possible to make that life as comfortable and as dignified and as pain free as possible. And most certainly I have nursed over the years people that has humbled me as what you have just said- what people can actually live through and what they can endure.

L: How strong the human spirit actually is...

S: Absolutely.

L: So it is not hopelessness it is actually in a sense hope...

S: Yes and something that over the years in spite of not much personal success in relationships and one on one love, I have built over the years a firm believe that love does make the world go round and situations like these are unique opportunities to give love and really make a difference to these people. You know when you rub somebody's back just because you have to do it and when you rub somebody's back because you really care it is two completely different functions and I think caring is essential and it makes all the difference in this kind of environment. If you care you will give that painkiller at two 'o clock and not at four 'o clock.

L: That also means you always in it, you know what I am saying, you in as sense in the suffering, it is always with you.

S: Ja, but it has been a life changing experience for me, honestly to have had the opportunity to have worked in this kind of environment in the years that I have. I don't believe that I would have learned much of what I feel I have anywhere else.

L: I suppose in nursing there are softer options?

S: Yes. Within that courage, we have somebody here who is dying of MS who, you actually, you need courage to into his room, that is the degree of suffering that we see here and he has been here for eight years, he still laughs , you know it truly teaches you so much about, he really is in agony almost all the time and as I say he has not the pleasures of eating, he does not have the pleasure of drinking, he has no human pleasures left, that is how sick he is, but he still laughs... so ja.

L: Anything else you would like to add?

S: No I have a secret wish and desire that nurses could be, could be trained to be more compassionate. I think we have lost it.

L: Do you think the profession has lost it?

S: Terribly, terribly within the hospital environments. You know the minute a profession starts to become very academic I think some of that automatically goes, obviously a personality type makes a difference, but in this country I also think one of the saddest things is that with the unemployment we experience many people are doing this because it is a job. It is a job, so you not getting the personalities in the profession that you are actually looking for and I have a daughter that is a medical student at the moment an she is witnessing cruelty, not just lack of caring within the hospitals from the nursing staff, literal cruelty. And that distresses me terribly, because within our professions we hold tremendous power and if it is abused it is frightening.

L: And I think it is important that we as professionals recognize this power that we got. It is frightening what you can do with it and the impact you may have on others. If you not aware of that you may harm...

S: Definitely and it is something that when I speak to especially the level of nurses the caregivers, the auxiliary level, they are totally shocked when I make that statement when

I make it to them. You are abusing the power you have over this person when you leave them sitting in their own faeces for four hours and it is so important to recognise that that is what is happening, literally. Ja so that is all. I still believe it is a profession that needs more heart than head. I really believe that, not that I am discrediting the intelligence of anybody that is nursing or my own, I am just saying it's got to be a balance and there is a definite loss of the caring aspect within the profession.

L: Just on a personal level the fact that your daughter is a medical student, do you think you have influenced her in any way? She must have seen how hard it is?

S: I know. I think so, I think it did as a little girl and she built this dream to become a doctor and she is experiencing a lot of highs and lows. She is in her fifth year now and she does recognised the downs of the profession she has question it and have said things to me like - Mom, I don't know why I did this, I saw what you went through, but she is also a personality that when she went through her last crisis of am I doing the right thing, five and a half years later it is a hell of a question to be asking. And then we sat down chatted and I said to her you've got to ask yourself where else do you see yourself. She has a very deep, she is a deep person and there is nothing frivolous about her at all. She is not fashion conscious, she does not worry about makeup, she always been interested about life at the root level, you know. And that has made her feel a lot better. She said Mom... she had the brains to become an accountant, but Cathy in the corporate world is a no-no. She certainly would not fit in the secretarial kind of , so the health professions is where she belongs and whether in my mind no matter which member of that team you are it is not easy. We have not chosen an easy road, have we? We have chosen the road of people. So I think that has helped her to, but I suppose initially it did come from me, an exposure to the environment of medicine that gave her that dream.

L: My last question is: How was it to talk about this?

S: You know I did not think that I would be upset like that. So that has given me food for thought.

L: It was not my intention to upset, but I did found with all the interviews it does touch people. I think a lot of the time nobody actually ask how it really is...

S: I have touch on things today that I have not thought about for a while, like a reawakening. A realisation about what each day does involve and where is sometimes places you.

L: OK, thank you, should we stop there?

S: Yes, if you are happy.

Onderhoud met Carin

L: Ek dink die eerste ding wat ek jou gaan vra is maar net as ‘n dieetkundige, wat dink jy is jou rol? Hoe sien jy jou rol?

C: Om mense te help om hulle eetgewoontes en lewensstyl in terme van gesond eet te verbeter, sodat dit hulle lewenskwaliteit en hul gesondheid altesaam te kan verbeter.

L: Dink jy dat as jy daarvoor dink dat ons aan die einde van die dag eintlik baie... eintlik net chroniese goed is waarmee ons werk?

C: Wel, ek dink op ‘n manier is dit eers wanneer iemand met ‘n chroniese siekte gediagnoseer word dat hul meestal by ‘n dieetkundige aankom. Ek dink daar is mense wat voor ‘n chroniese siekte voor dit daar uitkom ‘n dieetkundige kom sien, maar omdat dit meestal, jy weet hoe is mense, hulle moet eers ‘n probleem hê – regtig siek wees voor hulle iets daaraan omtrent doen, voor hulle begin te wonder hoe moet ek eintlik eet en wat is gesond eet. So, meeste van die mense dink ek kom op die ou end eers by ons uit as hulle wel ‘n chroniese siekte het. Andersins eet hulle maar dalk wat hulle wil, want dit is nie vir hulle ‘n ‘issue’ nie, in terme van hulle gesondheid, hulle voel nie siek nie, verstaan wat ek bedoel. Dis gewoonlik as iemand eers siek voel dat hy begin te ‘worry’ oor eet hy reg.

L: Die feit dat ons werk met goed wat spesifiek chronies is, wat nie noodwendig beter gaan word nie – dink jy daar is enige frustrasie daarom?

C: Vir ons of die pasiënt?

L: Vir ons in ‘n mate, omdat jy weet dis nie iets wat jy noodwendig gaan reg dokter nie- jou rol is meer om dit te ‘manage’ ...so goed kan erger word nie noodwendig beter nie?

C: Man, ek kan nie regtig sê dat dit al vir my ‘n vreeslike frustrasie was nie, ek voel tog, jy weet, baie keer is dit ‘n geval van die persoon voel dan beter, dis nie in ‘n sin dat sy siekte gaan weg nie, maar hy kan ten minste sê maar hierdie simptome of my opgeblasenheid as dit Irritable Bowel is, my bloedsuiker is beter gekontroleerd, my energie vlakke is beter, ek voel net soveel beter, my slegte simptome van lae en hoë bloedsuiker is nou weg, so ek dink vir my as ‘n professionele persoon kry ek nog steeds, jy weet ‘n.... wat is die woord...

L: Ja, ek weet wat jy sê ... wat ek wil sê is dat omdat ons nie kan meet in terme van dat ons mense gesond kan maak nie...

C: Is dit vir my frustreerend?

L: Maar dit klink vir my jy kry wel goed wat jou laat voel dat dit wat jy doen is...

C: ...is die moeite werd. Yes.

L: Hoekom dink jy kom mense ooit na dieetkundiges toe? Hoekom gaan lees hulle dit nie net in 'n boek nie of gaan net op die Internet nie?

C: Ek dink die informasie daarbuite is besig om – of te hoog of hulle verstaan dit nie, of die een ding sê so en die volgende ding sê presies die teenoorgestelde of hulle weet nie hoe om dit prakties te implementeer nie. Ek vat nou byvoorbeeld die goed soos die glisemiese indeks, 'n mens kry al die glisemiese indeks resepteboeke, daai teksboek, “Eat smart, stay slim” , al daai goed en ek het al mense gesien wat al die boeke het, hulle het dit alles gelees, hulle verstaan as hulle dit lees, maar hulle weet nie hoe om dit prakties te implementeer en hoe om vir hulle self 'n eetplan te hê om te volg nie, hulle weet nie hoe om dit te implementeer nie, hoe om dit prakties te maak nie.

L: Dink jy mense het behoefte aan daardie verhouding – om oorkant iemand te sit en te sê – dit is wat ek doen, wat dink jy moet ek doen- ...

C: Ek dink in 'n mate, ek weet nie of dit soseer oor die verhouding gaan nie, maar ek dink hulle het baiekeer iemand nodig, jy weet veral met goed soos gewigsverlies, jy sal dit doen, jy gaan dit doen, maar jy sal dit volgende week doen of volgende maand en dan kom jy net nooit daarby uit nie en baiekeer as jy half 'n fasiliteerder het of iemand wat sê doen dit hierdie week en dit teen volgende week, dan wil ek daai sien, ek wil jou opvolg – dit gee hulle net meer struktuur, jy weet en half spreekwoordelik daar is om hulle te monitor – nou moet ek dit doen, iemand kyk wat ek doen. So, ek dink nou nie in 'n sin van die spreekwoordelike iemand wat die stok wat hulle dan moet dophou, ek bedoel dit nie in so 'n sin nie, maar in 'n sekere mate het iemand baie keer daai iemand nodig om hulle te help om actually op die regte pad te kom en te bly.

L: So mense wat in ons kantore inkom, sien ons as die 'expert'? Is ek reg?

C: Ja.

L: En is dit die rol wat ons vervul?

C: Yes, yes hulle sien jou as die ‘expert’ en hulle wil hê jy moet vir hulle die kennis gee en presies wat hulle prakties moet doen en baie keer as hulle die kennis het, gaan dit meer oor die praktyk. As iemand kom sonder geen kennis gaan dit in die eerste plek oor die kennis, eers later oor die praktyk, prakties wat hulle moet doen, maar as dit iemand is wat die kennis het gaan dit oor hoe moet ek hierdie kennis implementeer, maar daar is wel mense wat kom vir die spreekwoordelike ‘ek soek iemand om my dop te hou’

L: Vir ‘expertise’...

L: Dink jy ons opleiding, ek dink jy ook nog, alhoewel jy jonger as ek is, ons is baie streng opgelei volgens die mediese model – daar is ‘n diagnose en daar is ‘n behandeling en jy word amper geleer om die siekte te ‘manage’...

C: Assessment...

L: Dis ‘assessment’, dis ‘implementation’...

C: ‘Implementation’, daai tipe van goed ...

L: Ja, daar is stappe en die fokus is baie op die siekte en nie noodwendig op die persoon nie?

L: Kan jy vir my sê wat jy dink van daardie stelling?

C: Ja, kyk hoe kan ek sê, ek het spesifiek by Pretoria geswot, waar ons wel nie net BSc, maar B Dieetkunde het, omdat dit gekombineer is met sielkunde. Nou kan ek vir jou sê ons het sielkunde gedoen as ‘n vak en dan het ons voeding gedoen as ‘n vak, maar ons het nooit die twee geïntegreer nie.

L: ...dit is ‘n belangrike punt...

C: So, dit is defintief beter dat ons ‘n meer sielkundige agtergrond gehad het, maar dis nooit werklik geïntegreer nie, so dis half letterlik...

L: So dit is twee aparte vakke...

C: Yes, so die sielkunde of die menswees nooit vreeslik toegepas in dieetkunde self.

L: En in praktyk moet jy dit eintlik integreer.

C: Ek dink selfs aan daai van as dit so ‘n persoon dan...

L: Die persoon wil visueel gestimuleer, die persoon wil...

C: Presies, daai soek detail, daai soek glad nie detail, jy weet daai tipe van goed. En in ‘n mate probeer ‘n mens bewus wees daarvan en dit implementeer, maar ek dink nie dit was

genoeg gestress op universiteit nie. Ek dink in 'n deel toe ek daar was het hulle begin om dit te doen, maar ek dink nie dit was genoeg nie.

L: Maar dink jy nie dis as jy jousef sien in praktyk die afgelope hoeveel jaar, dink jy nie 'n mens begin 'n sensiwiteit ontwikkel vir die persoon oorkant jou nie? Jy kan 'n gevoel kry waar daardie persoon vandaan kom as jy luister na sy opmerkings, jy kan sien as hy half 'defensive' is dis goed...

C: Jy tel dit op en dit kom definitief met ondervinding. Jou luistervaardighede en jou mensanaliese word net al hoe beter. Jy kan sommer dadelik sien die persoon het nog nie sy diagnose aanvaar nie, of hy het of hy is negatief of hy is positief, dit begin 'n mens definitief baie makliker optel, hoe langer jy daarmee werk.

L: Is hierdie werk nog vir jou bevredigend?

C: Yes, nee definitief, en ek dink in vergelyking met baie ander professies, is daar darem wel 'n mate van 'reward'...jy weet 'work reward, omdat jy kan van mense hoor dat...

L: Wat is daardie 'rewards' vir jou?

C: Dat ek vir iemand kon help...

L: En hoe weet jy dit?

C: Jy moet 'obviously' die persoon weer sien, so baiekeer weet jy dit nie, baie keer sien jy nie weer die persoon nie dan kry jy nie weer daardie 'reward nie', so as jy weer die persoon kan sien en tesame het julle dit nou reg gekry om een of ander simptome of iets te verbeter dan is dit vir my 'rewarding', maar jy gaan dit nie noodwendig weet nie. Jy gaan dalk 'n persoon sien en jy gaan dalk se dit of dit behoort jou te help, maar dan sien jy dalk daardie persoon nooit weer nie. Dis half... jy weet nie, het dit gehelp en dit gebeur 'obviously' ook baie van die tyd dat hulle jou nie weer kom sien nie. En dit is tweerlei - partykeer het dit gehelp en daarom voel die persoon 'ag wat, dis oraait ek hoef nie weer terug te kom nie' of partykeer het dit glad nie gehelp nie en hy dink OK dit het glad nie gehelp nie ek gaan nie terug nie, waar jy weer pasiënte kry wat spesifiek terug kom en slegs dan kry jy daardie 'reward'.

L: En is dit genoeg vir jou?

C: Dis vir my goed. Ek dink daar is baie ander werke waar 'n mens nie 'rewards' het, behalwe geld nie. So ek voel jy weet dat dit wel 'n mate van 'reward' vir my gee. Ek dink wat miskien, waar die frustrasie miskien inkom is meer by 'weight loss' – dis ook

chronies want daar is baie meer faktore betrokke, dis nie net ek is nou siek, so ek moet nou dit en dit doen nie, om my gesondheid te verbeter nie. ‘Weight loss’ is ook ‘n baie sielkundige ding en dis nie noodwendig dat die persoon jou raad gaan volg nie en dan kom hulle gewoonlik terug en blameer jou, omdat hulle nie bereik wat hulle wou nie...

L: Ek dink dit is ‘n belangrike punt, want dit sluit aan by wat ek wil vra. Voel dit partykeer vir jou asof die pasiënt wil hê, jy moet verantwoordelikheid vat vir sy siektetoestand, asof hulle half na jou kyk as die gewig nie afgekom het nie en die bloedsuikers ...

C: Nee, verseker, verseker...

L: ... want jou raad het toe nou nie...

C: Presies, yes. Daar is definitief die pasiënt wat dit op jou pak en dit is half jou skuld, want jy het nou nie reg gehelp nie en dit is nie noodwendig dat hulle presies gedoen het wat jy vir hulle gevra het om te doen nie. Jy het my nou aan iets anders laat dink ook – een ding waaraan jy my nou laat dink het is dat pasiënte baiekeer sê “jy straf my”. Dis vir my sleg. Hoekom moet ek...dis iemand wat nog nie gereed is om sy lewensstyl of sy eetgewoontes te verander nie, wat daardie houding van “ek wil nie ander eet nie, ek wil nie eintlik so maak nie” daai van “ek wil nie, wil nie so ek gaan nie so hoekom se jy ek moet hierdie goed doen”. Jy is half die slegte...

L: So die ‘anger’ is bietjie, want ek het gekry van die dokter dat partykeer is hulle vir haar kwaad oor die diagnose.

C: Yes, yes.

L: So jy kry daardie ou wat daar instap wat ‘n diabeet is en hy het dit nog nie eintlik deur die proses gegaan nie en jy verteenwoordig die persoon wat alles van hom gaan wegvat wat hy nog altyd geniet het?

C: ‘Exactly’. En dis presies baie keer hulle woorde “hoekom vat jy alles weg van my wat ek geniet” en ek bedoel ‘n mens probeer jou bes om hulle positiewe raad te gee en nie negatief te se moenie dit, moenie dit nie, maar ek bedoel daar is op die ou end sekere goed wat hulle moet verander, wat hulle moet los, wat hulle moet vermy wat ‘n mens nie noodwendig van kan wegkom nie. En ‘n mens probeer konsentreer op die positiewe,

maar tog die negatiewe en die goed wat hulle van moet wegbly bly nog steeds daar en dis baiekeer al wat hulle raaksien, as hulle veral negatief daarvoor ingestel is en hulle wil nie verander nie of hulle is nie reg om te verander nie dan gooi hulle dit na jou as dieetkundige, jy weet, want hoekom, “hoekom is jy nou so met my, hoekom straf jy my nou, hoekom maak ... so hulle reflekteer dit definitief op jou en...

L: Jy voel dit?

C: Jy voel dit, maar jy weet wat moet jy nou eintlik vir hulle se – ‘obviously’ is dit nie lekker om te verander nie, maar hulle moet dit doen, so hulle sien jou as die slegte een in die verhaal wat al hiedie goed sê, in ‘n mate blameer hulle dan die diagnose op jou.

L: En hoe hanteer jy dit?

C: Ja, partykeer, jy weet dit hang af van die persoon, dit hang af van die situasie, partykeer probeer ‘n mens dit so half vermy en ander kere probeer jy net half stress dat, hoe kan ek nou sê, jy probeer stress dat dit hulle regtig gaan help en in watter mate dit hulle lewe gaan verbeter en nie noodwendig gaan versleg nie. Ag, jy werk nou maar op...

L: Ek dink waarby ons probeer uitkom is dat partykeer kom mense met ‘n dubbele boodskap, hulle se “ek wil verander, maar ek wil eintlik nie verander nie?”

C: Ja, ‘exactly’, hulle is eintlik nie reg om te verander nie...

L: En dit is dan jou werk om vir hulle daardie inligting te gee, alhoewel jy miskien weet dat jy gee al hierdie informasie, maar miskien is hulle nie reg nie?

C: Absoluut, Linde, ek gaan vir jou se mens probeer nou half vir hulle te vertel om gewoontes te verander is nie lekker nie en dit vat tyd en dit is ‘n ‘uphill’ ding en op die ou end is jy bo en jy het nuwe gewoontes en dit is nie moeilik nie, so ek probeer altyd daarop stress dat in die begin is dit moeilik en dit vat tyd en op die ou end is dit net die moeite werd in terme van hulle gesondheid en hoe hulle voel en dat dit op die ou end nie meer so moeilik gaan wees nie, so ek probeer half ditvir hulle verduidelik, maar as hulle nog nie reg is om te verander nie gaan dit nie eers vir hulle ‘n positiewe verduideliking gee nie. En baie kere probeer ek ook net stress, jy weet, dit is nou wel so dat jy nou moet versigtig wees vir so en so, maar dit meer, so dit gaan nie net oor moennie, moenie, dit gaan ook oor die positiewe, meer van dit of dit gaan vir jou goed wees. Ek probeer baie

en dit is dalk ook hoekom ek ook altyd so lank vat, langer as eerder korter vat met 'n pasiënt, vir hulle verduidelik hoekom hulle 'n ding moet doen. So ek probeer altyd vir hulle verduidelik hoe dit hulle gesondheid gaan verbeter, m.a.w. as hulle dit insluit of as hulle dit verminder hoe gaan dit 'n positiewe effek he. 'Obviously' op 'n manier wat vir hulle maklike verstaanbaar is – in 'lay people's terms, jy weet, aangesien nie te medies nie, maar op 'n eenvoudige manier hoe dit bv. hulle bloedsuiker gaan verbeter. En ek dink as hulle verstaan hoekom hulle 'n ding moet doen is dit ook vir hulle baie makliker om dit te kan doen en om 'eager' te wees om dit te doen. So dit is maar half die goed wat ek probeer om die moeilike situasies beter te maak.

L: Dink jy partykeer baie keer kom mense by jou met 'n chroniese ding, maar hulle het eintlik nie 'n konsep van dat dit chronies is nie, dat hulle dink ... dat hulle dit erens misverstaan het en nie hulle kop om daardie ding gesit het – ja, ek is 'n diabeet vir altyd nie.

C: Ja, ek gaan nou die medisyne drink en so eet en dan sal dit weg gaan? Definitief en in kan jy my nou nie reg help nie, hoekom kan jy my nou nie gesond maak nie – ek betaal jou, ek kom sien jou sorteer my uit...En ek dink dit is ook die probleem met self met simptome... daai van ek kom nou terug en ons het netnou gepraat van gewig, maar ek het nog steeds, jy weet hardlywigheid, dis nog steeds nie weg nie.

L: en jy is die ekspert wat moet weet wat om te doen?

C: Ja en daar is gevalle wat 'n mens nie weet wat om te doen nie!

L: En dan... hoe voel jy dan?

C: Dan voel jy 'terrible' dan wil jy alles moontlik doen om die persoon te help maar jy weet regtig nie meer wat om te doen nie. Al wat 'n mens dan op die ou end kan doen half om die persoon na iemand anders toe te verwys. Dit is 'n slegte gevoel, want jy wil regtig waar die persoon help en die persoon word net nie beter nie – dis baie frustrerend.

L: So daar is 'limits to our skills'...?

C: Ja, absoluut, ons kan nie 'n 'magic wand' swaai en hulle is gesond nie. En ook omdat jy nie in beheer is nie m.a.w. jy kan vir hulle sê presies wat hulle moet doen, maar hulle gaan dit nie noodwendig doen nie en dit kan 'even' wees dat hulle jou dalk nie eers reg

verstaan nie. Ek bedoel baie keer het 'n mens so min tyd en jy probeer so baie informasie weergee dat hulle in elke geval die helfde of vergeet of misverstaan en dan bereik hulle nie wat hulle moet nie en dan jy weet is die probleem steeds nie opgelos nie. Dit is obviously hoekom ons na die tyd iets vir hulle gee op papier, jy weet iets prakties gee op papier.

L: Ek weet nie of jy al dieselfde ondervinding gehad het nie, maar partykeer is jy deur die hele proses en iemand kom terug en jy vra wat hulle doen en jy kom agter maar dis nie naastenby wat jy gese het nie en jy is so half 'stunned' dat jy half dink hoe kon...

C:..hoe kon hulle dit gemis het. Absoluut, self al, ek het al dan het ek 'n verskriklike goed uitgewerkte eetplan gestuur, eenvoudig, alles daar neergetik en dat iemand dan terugkom en dan of sê hy verstaan dit glad nie of hulle doen heeltemal die verkeerde ding en dan voel 'n mens so 'stunned' hoe is dit moontlik. Dis so eenvoudig, hoe kan hulle dit nie verstaan nie?

L: Dink jy dis moontlik dat ons partykeer mis waar die persoon amper emosioneel is?

C: Dit kan wees.

L: ...dat wanneer ons daai inligting oordra dat daardie persoon eintlik nie ontvanklik daarvoor is nie, want hy sit nog met, hy moet nog oor die diagnose kom, hy het nog nie regtig deur die proses gegaan om iets te doen nie?

C: En die probleem is jy het net daai uur, jy weet. En dit is nie noodwendig altyd maklik om iemand terug te kry nie, jy kan vir hulle se kom terug, dis belangrik daar is nog goed waaroor ons moet gesels, maar baie keer voel dit net so vir my – vrek gaan daai persoon terug kom, dis half die enigste kans wat ek het om iets oor te dra en dan dink ek net, omdat jy gepressure voel om alles moontlik in die konsultasie te gee – wat dan gebeur jy gee te veel en hulle is dalk nie reg nie, maar dis jou 'only chance', jy weet dis baie moeilik – dis vir my 'n 'catch 22' se dan nou eerder driekwart van die goed nie en dan is dit nou al wat hulle weet of gee jy nou maar die hele storie en hoop dat erens later maak dit vir hulle sin. Ek meen wat doen jy?

L: Dink jy ons weet genoeg van hoe dit is om met 'n chroniese siekte saam te lewe? Want ons is...ek het dit nogals besef toe ek met 'n matrone gesels het, sy het gepraat oor

‘nursing’ en ‘nursing’ daardie mense is by daardie persoon, heelyd en sy het gepraat van ander professies soos dokters en sy kon eintlik maar gese het dieetkundiges, want ons is geneig om in te gaan en uit te beweeg. Ons, maar dit is ons werk, dit is wat ons doen, maar ek wonder partykeer of ons genoeg insig het in terme van hoe daardie siekte werklik is om mee te leef?

C: Ek dink nie so nie, ek dink mens het dit eintlik net as ‘n mens self ‘n chroniese siekte het. Ek dink dit gee jou ‘n beter idee as jy iemand naby jou aan jou familie, iemand naby jou het, jy sien wat is die ‘everyday’ goed waarmee hulle sukkel en wat is hulle gevoelens en hoe tree hulle op, jy weet ek dink dit is anders as om dit net vir jouself te probeer indink as wanneer jy dit fisies sien of wanneer jy dit self ervaar. Ja, dit maak ‘n mens half... as om net sê gaan doen nou maar net dit, jy besef nie eintlik wat dit alles inhou nie, jy weet daai feit van wat dit werklik is, veral as dit ‘n lewens bedreigende siekte is, dink ek dit is ‘n ‘issue’.

L: Ek weet nou, soos jou skoonma het Diabetes en jou ma... so dis nie asof jy hier sit as ‘n leek met enige persoonlike ervaring oor wat ‘n diagnose kan doen aan mense van “ag ek gaan anyway doodgaan, kom ek eet wat ek wil”...

C: Dis ook hoe ek kan sien jy weet spesifiek in terme van dit wat hulle nou het, jy weet hoe hulle optree in terme van hulle siekte en hoe hulle en die moeilike ding waardeur hulle gaan en hulle sal byvoorbeeld Diabetes as ‘n voorbeeld partykeer absoluut goed wees en reg eet en alles en dan kom hulle net op ‘n stadium hetsy of dit is as gevolg van depressie of moedeloosheid of so –“ek gaan nou iets lekker” en dis maar waardeur pasiënte gaan, jy weet daar is stadiums wat hulle regtig doen wat hulle moet en dan is daar ander stadiums

L: Sou jy sê dat omdat jy op ‘n persoonlike vlak mense naby jou het, wat met chroniese goed sit ‘n groter sensitiwiteit om dit ontwikkel het, waar as jy nie daardie ervaring het nie is ‘n mens miskien geneig om ‘judgemental’ te wees teenoor pasiënte?

C: Ek dink jy is meer sensitief, jy verstaan dit eintlik ‘n bietjie beter. As jy nie dit nie noodwendig self ervaar het nie dan –“ag jy is sommer simpel of jy is net nie positief genoeg nie”

L: Ja, doen tog net wat ek sê asseblief?

C: Ja, jy weet, maar mense is mense, niemand is perfek nie, ons almal het foute, almal doen nie altyd wat hulle moet nie in alle opsigte is ons almal sondaars. Jy weet wat jy moet doen maar dis nie noodwendig wat jy doen nie, so ek dink dit maak 'n mens ook meer bewus van, jy weet, dat jy ook jou pasiënte moet aanvaar as hulle nie gedoen het wat jy gesê het wat hulle moet doen nie en net verder probeer motiveer.

L: En dat dit nie noodwendig 'n verwerping van jou is nie, maar dat daar vreeslike baie dinge in hulle lewe kon gebeur het of daar is baie ander dinamika wat daar aangaan, so dit is nie noodwendig 'n verwerping van jou nie?

C: Hoeveel kry 'n mens nie mense met gewigsverlies wat terugkom met "ek weet laas keer was ek nie reg nie, daar was te veel 'issues', ek kon nie bly by wat ek moes nie, maar nou is ek hier, ek is reg, kom ons doen dit. Jy weet 'n ervaring soos dit het 'n mens laat besef, dat baie keer het dit absoluut niks met jou of niks te doen met die 'prescribe' wat jy vir die persoon gegee het nie. Ek dink die moeilikste situasies is, is wanneer iemand jou 'up front' konfronteer en se "hoor hier" nou nie in sulke direkte woorde nie, maar hoekom kan jy my nie laat gewig verloor nie, jy weet, hoekom verloor ek nie, jy weet. Die moeilikste situasies is as iemand jou so 'up front' konfronteer. Ek dink dit is die moeilikse situasie om nog steeds te se "kom ons kyk, kom ons probeer iets anders", soos jy se daar is baie redes en baie keer probeer 'n mens maar se jy weet, kyk wat is al die bydraende goed en wat is die moontlike rede...

L: Want in 'n mate voel jy half verantwoordelik?

C: Ja, in 'n mate voel jy verantwoordelik, jy voel jy wil vir hulle verduidelik – OK, jy het tien teen een water, jy hou tien teen een water terug of jy weet, jy probeer half namens die pasiënt 'n rede soek of 'n verskoning soek hoekom nie gebeur het wat moes gebeur het nie, want jy voel verantwoordelik. En die frustrerende is daardie persoon wat elke keer terugkom en julle kom net nêrens nie, dis vir my die frustrerende. 'n Mens voel half jy weet nie meer wat om te doen nie.

L: Al ooit pasiënte gehad van wie jy nie hou nie?

C: Sjoë, dis 'n moeilike een. Kyk 'obviously' persoonlikhede verskil so daar is pasiënte met wie jy makliker oor die weg kom as ander. Ek sou sê pasiënte wat ek nou moet sê waar ek regtig ongemaklik gevoel het en nie van hou nie is tien teen een pasiënte wat my as persoon aangevat het- vir my, wat ek bedoel wat half, ek probeer nou aan 'n geval

dink, ek bedoel ek dink aan mense met wie jy soveel moeite doen en jy spandeer regtig tyd en moeite en so en dan sal die persoon agter jou rug of teenoor jou persoonlik half se jy het eintlik niks vir my gedoen nie, jy, my problem is nie opgelos nie, jy is niks werd nie of van ek het my geld gemors of ek het my tyd gemors, in die ‘mean time’ het jy soveel, baiekeer is dit juis iemand wat vir wie jy soveel moeite spandeer het of iemand wat sê“OK, ek skuld jou geld maar ek gaan jou nie betaal nie ,want ek het niks hier uit gekry nie. Dis nou half die pasiënte wat ek sou se ek nie van hou nie, want jy het eintlik vir hulle so baie gedoen en hulle toon geen waardering nie en is eintlik ‘nasty’ met jou ten spyte van die feit dat jy eintlik niks aan hulle gedoen het nie, jy wou hulle eintlik help. So ek dink dit sal klassifiseer as pasiënte waarvan ek regtig nie hou nie...ek het al snaakse pasiënte gesien en baiekeer is dit regtig pasiënte wat ook regtig moeilik is en jou nie ‘n kans gee om ‘n woord te praat of wat hoe kan ek nou sê, frustrerend is, jy vra hulle een ding dan en hulle praat, om hulle op die pad te hou ... oor ander, hulle familie en allerande ander goed, so dit is vir my ‘n frustrerende konsultasie as ‘n pasiënt wat jy heelyd half op die regtig...

L:...op die ‘topic’ moet hou?

C: Yes, want hulle donner heelyd af en praat heelyd ander goed en jy sukkel om hulle aandag te hou, maar dis nie te se dis pasiënte waarvan ek nie hou nie, maar dis moeilike pasiënte om mee te werk. Ek sou se pasiënte waarvan ek regtig nie hou nie, soos ek gese het is pasiënte wat persoonlik aantygend is of ‘obviously’ negatief is oor alles wat jy se is hulle negatief –dit is regtig moeilike pasiënte...

L: En dan dieetkunde val mos onder ‘n ‘health profession’ dis ‘n ‘helping profession’, so ek vra altyd hoekom dink jy is dit iets wat jy, Carin gekies het?

C: Ag maar dit is ‘obvioulsly’ dat ek daarvan hou om mense te help. Dit is vir my ‘rewarding’ om mense te kan help.

L: Kan jy, want as ek so met mense gesels dan kan ek amper half ‘link’ met goed wat hulle funksie in hulle gesin was of dat hulle die ‘rescuer’ is ...

C: Ek is ook geneig om die ‘rescuer’ te wees...

L: Want almal met wie ek praat en ek praat van myself ook, ons het daardie geneigdheid om die ‘rescuer’ te wil wees en ons sit dit voort nie net professioneel nie, maar in ander verhoudings ook...

C: Ek is geneig om 'n 'rescuer' te wees, ek sal byvoorbeeld, ek kan dit nie hanteer as daar struweling is tussen mense in terme van verhoudings nie m.a.w. dit grief my as mense kwaad is vir mekaar. Ek kan nie of dit nou ek wat kwaad is of heeltemal twee ander mense in my gesin- 'I want to resolve it' "Ag, man gaan praat jy nou" –ek hou nie van konflik nie, so ek wil altyd daai konflik...

L: En dinge beter maak vir mense?

C: Ja, ek sal altyd en ek is ook iemand wat altyd, ek sien myself as 'n positiewe mens en ek probeer altyd die positiewe sy van dinge insien, so as iemand se "hoor hier, maar daai persoon", iets slegs se dan probeer ek altyd die persoon se goeie kant kies al het die persoon iets verkeerd gedoen tipe van ding – ek probeer dit altyd half regmaak – 'shame' hy het moeilikheid by die huis of jy weet ek probeer dit verbeter.

L: Dink jy 'n deel van daai kom uit in jou as 'n professionele persoon?

C: Ek glo so, ek glo so, want as ek regtig iemand het wat negatief is of so dan wil ek hulle help om meer positief of dit nou oor gewig of hulle gesondheid of wat ook al te wees, maar ek bedoel jy kan ook net soveel doen in 'n uur, so ek probeer, ek bedoel in 'n sin jy probeer ook simptome en hulle eetgewoontes en alles regmaak.

L: As jy enigiets anders kon gewees het, wat sou dit gewees het?

C: Man, ek moet sê ek sou defintief nog iets gedoen het waarmee ek met mense werk, ek sal nie iets wou doen waat daar nie mense betrokke is nie, so ek sal altyd half met mense as sulks wil werk. Sjou, dit het nou niks met die 'topic' te doen nie, maar waarby ek ook nie altyd uitkom nie, ek is ook lief daarvoor om kreatiewe goeters te doen, hetsy dit is om iets te verf of om iets te maak of wat ook al en dit kry 'n mens nou nie noodwendig kans om te doen as 'n dieetkundige nie, so daar is nie altyd genoeg tyd vir die kreatiewe sy van my nie. Kan nie vir jou spesifiek sê daar is iets wat wou doen nie, my man het al baie keer vir my gesê hoekom doen jy nie heeltemal iets anders nie, hoekom kom werk jy nie as 'n 'whatever' by ons maatskappy nie en dis net goed wat dit net nie vir my doen nie. Soos met rekenaars, IT of iets jy weet, iets met syfers, dit doen dit net nie vir my nie. Ek stel net nie daarin belang nie. As ek iets nou moet gaan swot sal dit ook te doen hê met of biologie of mense of voeding of jy weet iets lewendigs en nie boeke en syfers nie.

L: So dit is belangrik deur die gevoel van jy help vir mense kweek dit 'n gevoel van waarde?

C: Ja, verseker, want my man het al gesê hy beny my, want hy dink, die woord is werksbevrediging, want ek dink in 'n sin ons kry nie altyd noodwendig die geldbevrediging nie, maar ons kry baie werksbevrediging deur veranderinge te sien, mense wat gewig verloor of mense wat beter voel of mense wat gesondheid beter is of wat ook al, maar jy weet dis ook nie honderd persent van die tyd dat jy dit sien nie, baie keer sien jy dit nie, jy hoop nou maar jy sien dit en jy hoop nou maar met die persoon het dit goed gegaan en dit het al baie keer so gebeur dat ek regtig iemand na 'n lang ruk gesien het en dan het hulle baie goed gedoen en dan het hulle en hulle het bereik wat hulle moes, jy weet net nie daarvan nie. En dan baie keer is dit lekker om te hoor "o, ag jy weet"...ek het nie weer die persoon gesien nie, maar hy het eintlik goed gedoen, maar daar is ook die 'down side' met die mense wat nie bereik wat hulle wou nie en dan voel 'n mens in 'n sin soos 'n 'failure' dan kry 'n mens die teenoorgestelde van werksbevrediging, want jy weet, het ek regtig waarde toegevoeg? Dan voel jy weer jy het niks bereik nie. Jy het nie die persoon gehelp nie en in die selfde opsig kan ek ook vir jou die teenoorgestelde van bevrediging gee. Voeg ek nou regtig waarde toe?

L: Wat ek nou maar net opgetel het deur met mense te praat is dat ons nie almal gaan help nie, ons gaan party mense help en 'n mens kan dalk op 'n punt kom wat jy kan sê dis OK?

C: Ja, jy kan nie almal help nie...Dalk ander later dit is dalk net nie die tyd nie...Ja, dit is nou maar, dis ook nie of ek regtig 'n 'issue' daaroor het nie, wat vir my in die agterkop meer 'n 'issue' is, is dat voeding raak so half 'n Jan Alleman ding, jy weet, elkeen ag homself as 'n 'expert' in voeding en ek dink dit is meer iets wat my nog altyd gepla het, nie so erg of mense bereid is, daai van...

L:... is ons nog die 'experts'?

C: Ja, jy weet, 'n ma is die 'expert' van haar gesin se voeding en elkeen ag hulle self as 'n 'expert' en hulle hoor by hulle ma en hulle ouma en ... En dan is daar hierdie mense wat intensief die internet en alles bestudeer en hulle weet partykeer 'even' van goed waarvan jy nog nie eers gehoor het nie, nie dat dit noodwendig goed is wat nagevors is nie, maar dis ook moeilik omdat dieetkunde so wyd is en 'n mens nie noodwendig spesialiseer nie, jy het nie die tyd om in detail na elke liewe dingetjie te kyk nie, van elke liewe ding 'n

studie te doen nie en al die nuutste goed uit te vind nie. En dan kom iemand na jou toe en dan voel dit partykeer sjoe, ek weet nie ...

L: En dit 'challenge' 'n bietjie jou 'expetise'?

C: Ja, so ek dink die moeilike deel van dieetkunde is meer daai van almal dink hulle weet alles van voeding en miskonsepsies wat daar is oor voeding en mense wat dink goed is goed vir hulle maar dis eintlik negatief vir hulle gesondheid, die goed wat in die mark is en diëte en produkte in die mark wat eintlik mense op die ou end meer skade aanrig as goed. Jy weet, daai goed is vir my die 'issues', dit is goed wat my pla. Dit is goed wat vir my moeilik is.

L: Ek dink waarby ek wil uitkom, want ek weet hoe baie 'n mens in 'n konsultasie insit en veral omdat ons met chroniese goed werk en soos jy sê jy het net daardie uur en jy moet al daardie goed inkry – het jy ooit op 'n stadium gekom dat jy amper nie meer mense wil sien nie? Amper soos 'n 'burnout'... Het dit al ooit gebeur?

C: Ja, ek dink nie noodwendig op die oomblik nie, maar op 'n stadium soos laas jaar as ek die hele dag, en jy sien iets soos ses of sewe nuwe pasiënte en op die ou end dan is dit vir my net so erg, ek kan naderhand nie eers meer onthou hoe hierdie persoon gelyk het nie, want jy het net soveel mense – dit was net so 'n 'overload' van informasie en mense en hulle probleme en 'issues' dat dit is asof ek net nie meer kan fokus nie. Jy weet presies onthou wat, veral as jy nou na die tyd vir iemand iets moet uitwerk en jy al sewe of ag goed wat jy moet doen maar jy kan nie presies onthou hoe jy regtig hierdie ding wou saamstel vir die persoon nie, want jy kan nie al hulle 'ins en outs' onthou nie. En as jy nou veral die selfde chroniese siekte en jy het nou vier diabete na mekaar gesien dan voel dit naderhand of dit by jou ore uitkom, want baie keer is dit goed wat jy moet herhaal, want as jy dit verduidelik dan moet jy sekere goed verduidelik en as jy dieselfde diagnose direk na mekaar heeldag sien, dan mot jy dieselfde ding oor en oor verduidelik en dan voel dit later asof jy 'n grammefoon is, nie dat jy noodwendig dieselfde goed sê nie, maar dis herhaling en op die ou end maak nie saak watter chroniese siekte dit is dit kom alles neer op gesond eet, so daar is sekere goeters wat dieselfde is vir almal en daar is sekere goeters wat jy vir almal moet sê of verduidelik of insluit erens op 'n manier en partykeer dan voel dit vir my, vir my voel dit dalk 'monotonous' of so vanselfsprekend, nie dat dit

noodwendig vir die pasiënt is nie, maar dit is ook partykeer vir my, so ‘basic’ dat dit voel half iemand anders kon dit geweet het...

L: Ja, hoekom sit die persoon om dit te hoor ... Dit is weer daardie ding van is ons regtig hierdie ‘eksperts’?

C: ..maar ek dink as ‘n mens die hoeveelheid mense wat jy op ‘n slag sien per dag beperk dan raak dit ‘n minder uitmergelende proses...

L: En sal dit meer bevredigend wees?

C: Ja, ek dink so anders is dit net soos ‘n masjien, jy weet, iemand in en iemand uit en jy het half nie die tyd om dit regtig te verwerk nie.

L: Enigiets nog wat jy wil bysit in terme van jouself of ...

C: Wat ek wil bysit in elke geval is ook dat pasiënte by jou kom en hulle verstaan nie hulle diagnose nie en as hulle nie verstaan wat hulle diagnose is nie, hoe kan hulle al aanvaar het, nou moet jy eers die verstaan werk, voor jy by die aanvaarding uitkom, voor jy kan uitkom by wat jy kan doen en ‘obvioulsy’ is dit onmoontlik om in een sessie te kan doen, so ek dink as ‘n pasiënt by ‘n mens kan aankom en hy weet al verstaan darem al wat met hom aangaan en die implikasies van die siekte, kon hy al ‘n bietjie tyd gehad het om dit te verwerk. So by die tyd dat jy hom sien is hy meer gereed, so ek dink... en die problem is dokters het ook nie tyd om dit vir mense te verduidelik nie ...

L: Niemand het tyd vir hulle nie?

C: Baiekeer is dit ons wat die tyd moet spandeer om dit te doen, want ek voel net ek kan nie vir iemand verduidelik wat om te doen en sy lewe te verander as hy nie verstaan hoekom nie. So, baie keer spandeer ‘n mens tyd daaraan en my ‘worry’ is altyd gaan die persoon weer terugkom, so ek het dit altyd in my agterkop, jy weet, so ek wil altyd half te veel as te min gee, want ek weet nooit of die persoon weer gaan terugkom nie en ek weet nie of dit verkeerd van my is nie, moet ek eerder maar min gee en hoop hulle kom terug- moet jy maar eerder net konsentreer op die diagnose of die aanvaarding?

L: Dis ‘n belangrike punt, want dit kan redelike implikasies hê vir hoe ‘n mens werk – ideal behoort jy te weet waar daardie persoon is en as daardie persoon net wil praat oor hoe erg dit is dat dit die siekte vir ewig is, dit sou ideal gewees het as jy kon, maar aan die einde van die dag is daar tyd ‘geallokeer’ vir jou om hom in te lig lewensstyl veranderinge...

C: Yes, en hy betaal om uit te vind wat om te eet, so dit help nie hy stap daar uit en jy het basies net vir hom gesê hy moet gereeld eet en hy het niks anders by jou gekry nie.

L: Ek dink dis daardie druk wat ons op self sit en ek dink dit kom van ons opleiding af om hierdie konsultasie regtig-regtig die moeitewerd te maak, maar jy kan daai uur spandeer en dit kan dalk niks vir die persoon beteken nie...

C: ...maar as jy niks vir hom gegee het nie...

L: ...dan het jy ook nie ...

C: ...waarvoor hy betaal het nie. In 'n sin die ideal sal wees as iemand kom en sê OK as 'n nuwe pasiënt, maak 'n pakket, ek moet vir drie konsultasies in die volgende twee maande kom, dan weet jy nou ons kan nou net konsentreer...

L:... veral met jou chroniese siektes, soos Diabetes is dit miskien goed, want ideal sou 'n mens nou net wou praat oor die diagnose en die implikasies van die diagnose.

C: 'Exactly' en 'geniune' die basics en hoe bloedsuiker kontrole werk voor jy nog kom by wat jy moet doen om dit te verbeter en dan kan jy nou sê dat as jy vir jou tweede konsultasie kom dan werk ons spesifiek hieraan. So ek dink die ideal sou wees as jy so 'n reeks konsultasies het, maar die probleem is, as 'n diabeet byvoorbeeld wat spesifiek 'n voorbeeld is, want dit is gewoonlik met hulle so by jou aankom wil hulle NOU weet wat om te eet, want hulle is bang iets gebeur met hulle. So hulle het daardie vrees en hulle selfs, jy weet as pasiënte bel om 'n konsultasie te maak wil hulle dan al weet wat om te doen, hulle wil nie nog 'n week wag om die dieetkundige te sien nie. So dit is die ander ding...

L: Ek dink wat jy sê is daardie twee boodskappe wat ons die heelyd kry – aan die een kant is dit die persoon wat oorkant jou sit en sê jy moet nou vir my sê wat om te doen, maar aan die anderkant is dit die boodskap van ek is nog eintlik glad nie reg om dit te doen nie...

C:...maar ek is bevrees ek gaan nou hier dood neerval...

L: En ek sê dit want ek doen dit self, jy probeer amper op altwee daardie boodskappe reageer en ek dink dis hoekom ons partykeer as daardie persoon uitloop dan wonder ons – wat het jy nou eintlik gedoen?

C: Ja...

L: Want jy wil reageer op die emosionele ding, hoe dit vir die persoon moet wees in dit, maar aan die ander kant ‘demand’ daardie persoon dat jy vir hom moet sê wat om te doen.

C: En ek vind, wat dan gebeur is en ek bedoel jy kom nou heeltemal by ‘n waar ding uit, is eerste deel van die konsultasie spandeer jy nou aan daardie emosionele sy of die diagnose of die komplikasies of ‘whatever’ verduidelik, maar op die ou end is daar so min tyd oor om fisies te sê vir die pasiënt oor wat om te doen dat jy daardie laaste stuk eintlik aframmel en te veel informasie in te kort tyd gee en dan dink jy juis ‘oh sherbet’ gaan die ou enigsins kop of stert uitmaak...

L: En miskien is dit weer daardie ding van miskien het jy die persoon gefaal?

C: Presies en weet jy wat, ek het al en jy weet dan probeer jy, soos jy sê ‘all to cover everything’ en dan op die ou end het ek al gesien dan probeer ek partykeer hou by vreeslik ‘basic’ en min goed of ‘even’ gee al die detail, maar dan sê die pasiënt vir my “nou, OK wat moet ek eet?”...

L: En hoe voel jy dan?

C: Nadat ek al presies vir hom gesê het eet dit saam met dit en jy het ‘genuine’ ek bedoel jy het eerder op ‘n praktiese manier vir hulle verduidelik hoe gereeld hulle moet eet, presies wat hulle moet eet en dan sê hulle nog steeds vir jou, dan sê jy nou vir hulle jy sal nou hulle eetplan e-mail of so dan vra hulle maar more of oormore, wat moet ek nou eet? Maar jy het nou alreeds vir hulle gesê presies wat hulle moet doen, maar dit is net asof hulle- nou wat moet ek doen- jy weet... Jy het nou net vir hulle gesê hulle moet spesifiek vrugte tussenin eet, hulle moet eerder kos saamvat as om te koop by die werk. Jy het alles vir julle gesê, maar dit is net half asof...

L: ...hulle integreer dit net nie?

C: ...so wat moet ek nou doen? Al het jy, maar soos ek sê dit is nie asof ek net teoretiese goed op hulle afgerammel het nie, dis praktiese goed waaroor ek met hulle gesels het. Dis nie met al die pasiënte so nie, maar daar is regtig van hulle, sjoe...half bevrees as hy nie ‘n papier voor hom het nie, weet hy nie wat om te doen nie. Ek dink dit is ook op die ingewing van die oomblik...

L: Ek dink dit is ook dalk die ‘society’ waarin ons leef – mense soek ‘n ‘quick fix’ –so hulle wil by jou inloop en in basies tien minute weet wat om te doen. En ek dink ons

‘respond’ op dit, want dit is wat van jou verwag word, maar êrens hier diep binne weet jy daar is meer aan dit?

C: Ja, ja...

L: So ek dink dit is die konflik waarin jy werk of sit.

C: Dis moeilik, maar dit is die ding mense soek ‘instant results’ – hulle is nie reg om dit te kry nie, maar hulle wil die ‘results’ hê...

L: En dit is miskien die ‘pressure’ wat ons ervaar?

C: ‘Exactly’ en gewigsverlies is ‘n tipiese voorbeeld, hulle soek nou die ‘results’, dit gaan hulle ‘n baie lang tyd vat, maar hulle soek nou die ‘results’ en jy moet hulle NOU ‘fix’ en dit is maar dieselfde met die chroniese siektes, hulle wil nou...

L: En ek dink wat daar ook speel is die persoonlikheidstipe, as jy die tipe persoonlikheid het wat die verantwoordelikheid wil neem, wat die ‘rescuer’ is wat dit wil beter maak, dan val jy vir dit, jy reageer daarop...

C: Ja, jy wil help...

L: En, wat veral met die dokters uitgekom het, ek weet nie of dit so erg vir ons is nie, maar mens kyk na ‘boundaries’, ek weet nie hoe jy voel nie?

C: Wat bedoel jy met ‘boundaries’?

L: Daar is ‘n punt waar jy moet kan besluit dat ...

C:..jy het nou jou deel gedoen?

L: Ja, of as jy agterkom daardie persoon plaas alles raak jou verantwoordelikheid en jy is op die ou einde die een wat die hardste werk, en die hardste sweet...

C: Dan moet jy kan terugstaan en sê “hoor hier, dis jou verantwoordelikheid”...

L: ...en jou keuse?

C: Ja, en ek bedoel daar ... en ek het dit ook al vir pasiënte gesê, jy weet, ek sê vir jou dit is wat vir jou gaan help, maar dit is nog steeds jou keuse of jy dit gaan doen, jy weet as dit iemand is wat baie negatief is dan maak jy dit duidelik, ek sê nie nou vir jou moet nou gaan en dit gaan doen nie, die ‘ball is in your court’, maar ek sê vir jou dit gaan vir jou help as jy dit gaan doen en baie keer, ek stress dit ook vir mense veral as daar baie goed is wat hulle moet doen, jy weet dit is soveel goed, maar ‘just go, and even’ al doen jy net een, begin net êrens, want dit is al hoe jy verandering gaan kry, begin net êrens en dat ek nie nou van jou gaan verwag om dadelik heeltemal te verander nie, maar begin net en as

jy dan terugkom na my toe wil ek ten minste sien dat jy al begin werk het om een of twee goed te verander dan kan ons verder werk aan dit wat jy nie reg gekry het nie, maar net so dat hulle voel, anders loop 'n pasiënt uit en sê "sjoe, ek gaan dit nooit kan doen nie" en dan los ons dit maar- so dis belangrik om êrens te begin.

L: So dis belangrik om hulle te 'empower' dat hulle voel hulle kan dit doen?

C: Yes, en vir hulle laat verstaan dat dit tyd gaan neem en dat niemand dit van hulle verwag om dit binne, jy weet in 'n uur reg te kry nie. En ek dink, nie noodwendig dat ek dit in die begin van my professie so gedoen het nie, maar ek is baie meer met tyd bewus daarvan om...ek dink in 'n mate verander 'n mens jou konsultasie styl soos wat jy ondervinding op doen, konsentreer ek baie meer daarop om vir mense te laat verstaan dat ek nie gaan dink hulle is 'n 'failure' as hulle nie honderd persent gedoen het ...ek verwag dat hulle net 'n persentasie doen van wat ek vir hulle gesê het, net om êrens te begin en dat ons nog daarop sal voortbou, jy verstaan wat ek bedoel, dit is van die goed wat jy verander...En dit kom in by 'you must remember, this is a person', waar voorheen eers jare vroeër was dit half dis wat jy moet doen en daar gaan jy ...

L: 'You treat the illness'...?

C: Ja, jy is 'n diabeet so jy moet dit nou dit doen en jy verwag maar die persoon moet dit doen en daar gaan hy weg. Nou, jy weet hy gaan nie alles doen nie, jy weet hy gaan dit dalk nie prakties noodwendig alles kan reg kry nie. So dit is omdat 'n mens besef maar hierdie is 'n mens en dit is nie noodwendig vir hom maklik nie, daar is 'issues' en daar gaan goed wees wat maklik is om te verander en daar gaan goed wees wat moeiliker is om te verander. En dit is half 'n voorbeeld van waar 'n mens die menswees inbring. En op sulke goed het jy glad nie gekonsentreer nie op universiteit nie. Dit was 'n diabeet en dis hoe jy dit behandel en ons het altyd gespot, want jy praat altyd, jy praat nie van meneer so-en-so nie, jy praat van die diabeet en die ou met die nierversaking en dis kankerpatiënte...

L: En dit is 'n baie belangrike punt wat jy maak want dit is 'n 'label' wat daardie persoon het en daardie persoon is 'n diabeet, maar hy is 'n mens, hy is 'n ma of 'pa of 'n dit of 'n dat...daar is 'n hele mens om daai...

C: Yes, en ek dink wat uiters belangrik is wat dit aan betref is 'n goeie 'assessment', want ek weet baie dieetkundiges doen dit nie of nie dieselfde tipe 'assessment' nie, maar almal

‘assess, want ek dink dit is juis in daardie ‘assessment’ van ‘n persoon se dag, van sy lewensstyl waarin ‘n mens optel wat is die ‘issues’ – is daar ‘n gejaagdheid, daar is nie tyd om its te doen nie, is daar ‘family issues’, pa koop ek kan nie sê wat hy moet koop nie, jy weet, sulke goed tel ‘n mens net op in die ‘assessment’. Jy tel net op daardie persoonlike ‘issues’ en daardie sielkundige ‘issues’ in die ‘assessment’, daardie tyd wat jy met die persoon praat en jy kyk na hoe hulle reageer en baie keer noem hulle goed wat jy nie vra nie, maar dis hoe jy hulle leer ken. So daarop kan ‘n mens reageer en jou eetplan daarby aanpas en as jy nou nie so ‘n ‘assessment’ gedoen het nie en gesê het “OK jy is ‘n diabeet, so as jy ‘n diabeet is moet jy so maak en so maak – dan gaan jy baie goed mis, dan gaan jy mis dat hierdie persoon eintlik glad nie kook nie of jy gaan dit mis dat hierdie persoon het nie geld nie of jy gaan dit mis dat hierdie persoon hou nie daarvan om voor ander mense tee et nie of jy weet, jy gaan nie by sulke goed uitkom as jy nie ‘n ordentlike ‘assessment’ gedoen het nie.

L: Soos wat ek eintlik hoor, ‘n mens kan amper daardie ‘assessment’ vervang met ‘n gesprek, jy moet ‘n doodnormale gesprek met iemand hê oor waaroor gaan sy lewe, wat gebeur in sy lewe...

C: En dis absoluut ‘crucial’ en wat vir my nou interssant is, ons kry ‘obviously’ doen dokters ‘assessments’ maar ek dink dit is meer net van “ja”, “nee” kort van tipe vrae, “is jy ‘n diabeet of nie?” “het jy enige chroniese siektes?”, so dit is nie regtig gespreksvrae nie, dis nie oop vrae nie, dis geslote vrae en as dieetkundiges vra ons ook baie oop vrae en pasiënte gee baie ander inligting wat ‘n mens nie eers noodwendig vra nie. En ek dink dis een van die goed wat tekort skiet by dokterskonsultasies, want daar is dalk baie goed wat hulle so mis en dan gaan net oor die diagnose...ek weet nie, ek is nie ‘n dokter nie, maar dis half my persepsie daarvoor. Dat hulle dalk nog meer ‘even’ op die diagnose konsentreer as wat ons noodwendig doen.

L: Ek dink partykeer, ek kry partykeer daardie gevoel as die persoon op daardie bank sit dan wil hulle net praat...

C: Ja, partykeer gaan hulle so van die paadjie af en ek het al gehad, dan is dit ‘n opvolg pasiënt, ‘even’, dan gesels hulle van dit en dat en dan sê hulle ek is nie nou by ‘n sielkundige nie, maar...want hulle kry die geleentheid om met iemand praat en ‘n mens

moet hulle daardie geleentheid bied, maar die grootste ‘issue’ is ‘time-constraint’ – jy het nie noodwendig tyd om na al die pasiënt se ‘issues’ te luister nie of te adresseer nie.

L: En saam met dit moet jy ook altyd jou rol onthou, want jou rol is nie noodwendig al daardie ander dinge ook nie?

C: Presies, jy moet daar by uitkom, maar...

L: Dis weer die twee boodskappe, wat is jou rol en wat is die behoeftes van die persoon en dis net my persoonlike opinie, maar die twee kom nie altyd bymekaar uit nie...

C: Presies en die pasiënt voel nou goed, want hy kon al hierdie goed vir jou sê, maar as hy daar uitstap en jy het vir hom geen voedingsadvies gegee nie gaan hy voel al het na hom geluister gaan hy nog steeds voel, sjoë, ek het nie eintlik gekry waarvoor ek gekom het nie.

L: En ek dink anderom ook...

C: ...want jy het vir hom gegee wat hy nodig gehad het, hy het nodig gehad dat jy na hom luister, maar hy het ook die voedingsadvies nodig gehad.

L: En dis miskien partykeer waar ons voel ons faal. Ek weet nie?

C: Ek probeer nou maar ‘it all cover’, jy weet, dan spandeer ‘n mens noodwendig langer as wat jy moet, of jy kom nie by alles uit wat jy moet nie, of jy rammel af goed, ja, dis die gevolge.

L: Enigiets nog? Wat ek moet vra – hoe was dit vir jou om hieroor te gesels?

C: Dit was oraaït, ja-nee. Ek bedoel al wat ek kan sê as jy dink jy gaan dit en dit sê, ek het nie noodwendig gedink oor wat ek gaan sê nie, maar terwyl ‘n mens praat dan dink jy aan kwessies, dan kom dit by jou op, jy weet, waarvan jy nie regtig bewus was nie. Terwyl jy daaroor praat, dan ‘click’ jy, “oor maar” – dan dink jy dit is eintlik ‘n ‘issue’ en dit is eintlik so dat dit konflik is, maar jy is bewus daarvan in jou onderbewussyn, maar dit is nie asof jy heeltyd daaroor dink dink nie – jy gaan maar net aan...