

**SENSE OF COHERENCE
IN LEPROSY PATIENTS**

by

JAMES ROBERT SCOTT

submitted in accordance with the requirements
for the degree of

DOCTOR OF LITERATURE AND PHILOSOPHY

in the subject

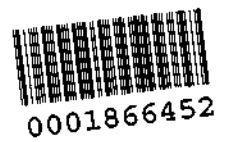
PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

PROMOTER: PROF C MOORE

JUNE 2006



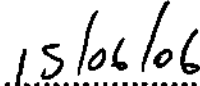
TO AMUNDA

Student number: 3306-499-7

I declare that **SENSE OF COHERENCE IN LEPROSY PATIENTS** 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.



.....
MR JR SCOTT



.....
DATE

UNISA LIBRARY
9 - OCT 2006
CLASS

ACCESS



ABSTRACT

Little research is available on the coping mechanisms commonly used by leprosy sufferers to adjust to the comprehensive psychosocial implications of this disease. This study was aimed at giving leprosy sufferers the opportunity to tell their stories of living with a chronic illness and to express their opinion on how they are coping. The SOC (Sense of Coherence) conceptual framework of Antonovsky (1987) served as the point of departure in order to study the various coping mechanisms used by leprosy sufferers. Participants were selected in terms of the high SOC scores they obtained on the Life History Questionnaire. Semi-structured interviews were conducted with the participants. Their stories were analysed and examples from the stories used to illustrate how the SOC themes were revealed. Related emerging themes were also identified. Ten common themes that describe the shared and unique ways in which the participants cope with leprosy, were identified. The results of this study highlight the importance of spreading stories of encouragement, such as those articulated in this study, to serve as a source of inspiration to others who suffer from chronic illnesses such as leprosy.

ACKNOWLEDGEMENTS

As my mother tongue is Afrikaans, I would like to take the liberty of doing some of the acknowledgements in my home language. My opregte dank aan:

Professor Cora Moore, my promotor en 'n huishoudelike naam die afgelope paar jaar in ons tuiste. U vermoë om my menswees te akkommodeer en deurlopend eerlike, substansiële en onmiddellike terugvoer te gee, gaan my altyd bybly.

Amunda, my vrou en beste maat. Ek is so dankbaar teenoor jou dat jy in die moeilikste tye positief gebly het, en my altyd hierdie ideaal gegun het. Die feit dat jy hierdie akademiese pad al gestap het en jou ervaring met my gedeel het, was van onskatbare waarde.

Eli, Amber, James en Kate. Ek waardeer julle eindelose geduld met Pa se gesit voor die rekenaar.

James en Rina Scott - my ouers. Dankie vir jul deurlopende ondersteuning. Jul sendingharte het my genoop om anders na leprosyers te kyk. En natuurlik my familie en skoonfamilie – ek waardeer jul konstante motivering.

Laura, my kalm assistent. Dankie vir (onder andere) die aanstuur van talle dokumente.

My grateful thanks to:

The management team and personnel of the Leprosy Mission. In particular to Mr Theo de Villiers, vice-director of this organisation, for his continuous support. Furthermore, to Ms Elena Jordaan, previously employed by the Leprosy Mission, who made this study practically possible.

The participants in this study. Thank you for sharing your precious stories, and for making this study possible.

James Scott

15 June 2006

TABLE OF CONTENTS

CHAPTER 1: MAPPING OUT THE CONTEXT: AN INTRODUCTION	1
Background	1
Aim and rationale of the study	3
<i>The design of the study</i>	3
A personal statement	4
Sampling and selection	5
Collecting the information	5
Analysis of the data	6
Presentation of the study	6
Conclusion	8
CHAPTER 2: LEPROSY – THE NON-EXISTING ILLNESS?	9
Introduction	9
Leprosy defined	9
Clinical manifestations of leprosy	10
Types of leprosy	12
Indeterminate leprosy (IL)	12
Tuberculoid leprosy (TL)	13
Borderline leprosy	15
Lepromatous leprosy(LL)	16
Reactional states	20
Transmission of leprosy	21
Susceptibility	26
Epidemiology	26
Treatment of leprosy	29
Prognosis of leprosy	34
Prevention of leprosy	35
Rehabilitation of leprosy patients	37
Concluding remarks	38

CHAPTER 3: THE PSYCHOSOCIAL STRESSORS OF LEPROSY PATIENTS: THE TURMOIL OF SOCIETY'S PARIAHS	39
Introduction	39
The psychosocial turmoil associated with leprosy	40
The incidence of psychiatric disorders in leprosy patients	41
Suicide by leprosy patients	43
Gender differences in coping with leprosy	44
Knowledge and treatment seeking	44
Impact on daily life	47
Interaction with the community	48
Impact of leprosy on marriage life	48
Impact of leprosy on family life	49
Stress induced by the community	52
Stress related to segregation and institutionalisation	52
The role of stigma on the psychosocial functioning of leprosy sufferers	56
Definition of stigma	56
The stigmatisation of leprosy sufferers	56
Six dimensions of stigma	57
The role of religion in the stigmatisation of leprosy sufferers	61
The role of medical aspects in the stigmatisation of leprosy sufferers	63
Appeasing the myths about leprosy – the stigma persists	64
The impact of facial deformities on the psychosocial functioning of leprosy patients	65
The impact of leprosy in the workplace and on the mobility of patients	66
The role of medical professionals on the psychosocial functioning of leprosy patients	67
The role of religion in dealing with psychosocial stressors	69
Overcoming the stigma of leprosy	70
Conclusion	72

CHAPTER 4: SENSE OF COHERENCE: A FOCUS ON STRENGTHS	75
Introduction	75
Evolution of a new perspective	75
The salutogenic orientation	77
The pathogenic orientation to health	78
The salutogenic perspective	79
Sense of coherence	82
The SOC and generalised resistance resources	83
Strength and development of the SOC	86
The development of the SOC over the lifespan	89
Infancy and childhood	90
Adulthood	91
Demographic variables and the SOC	92
Salutogenic constructs	93
Selection of specific salutogenic constructions	94
Hardiness	94
<i>Commitment</i>	95
<i>Control</i>	96
<i>Challenge</i>	96
Locus of control	96
<i>Internality as a reflection of the objective situation</i>	97
<i>Internality and culture</i>	98
<i>The concept of powerful others</i>	98
<i>Responsive versus defensive internality</i>	98
Self-efficacy	99
Learned resourcefulness	101
Macrosocial factors	103
Individual versus social responsibility	104
Spiritual aspects	107
Conclusion	108

CHAPTER 5: TREADING ON HOLY GROUND: THE RESEARCH APPROACH	110
Introduction	110
Defining qualitative research	111
Collecting the information	114
Qualitative interviewing	115
Recording observations	118
Strengths and weaknesses of qualitative field research	120
Validity	121
Reliability	121
The qualitative approach in the present study	122
Participants and procedures	122
Main study	123
Ethical issues	127
Research location	127
Qualitative research designs	129
Grounded theory	129
Historical Background	129
Grounded theory and related characteristics	130
<i>Theoretical sensitivity</i>	133
<i>Literature as a source of data</i>	133
<i>Theoretical sampling in grounded theory</i>	134
<i>Theoretical sampling in the present study</i>	135
<i>Constant comparative analysis</i>	136
<i>Data preparation and analysis in the present study</i>	136
<i>Coding and categorising data</i>	138
<i>Integration of theory</i>	141
Evaluative questions	142
Critique of methodology	142

CHAPTER 6: ENTERING THE KALEIDOSCOPE OF STORIES: THE THEMATIC ANALYSIS	145
Introduction	145
Participants	146
Participant A: Grace	146
Participant B: Busi	157
Participant C: Sara	165
Participant D: Mali	173
Participant E: Ziqie	179
Participant F: Peter	187
Participant G: Janie	198
Participant H: George	204
Participant I: Passion	213
Participant J: Jalo	220
CHAPTER 7: SYNCHRONISING THE INTERFACES: A COMPARATIVE ANALYSIS	227
Introduction	227
Confusion versus hope	227
Ignorance versus knowledge	231
Blaming versus taking responsibility	233
Distance versus closeness	235
To conceal versus to reveal	238
Passivity versus activity	239
Weakness versus strength	241
Entrapment versus transcendence	246
Dependence versus independence	250
Peculiarity versus sameness	252
Conclusion	254

CHAPTER 8: THE VOICES OF LEPROSY SUFFERERS HAVE SPOKEN:	
CONCLUSION	255
Introduction	255
Evaluation of the study	255
Strengths of the study	257
On a personal note	259
Limitations of the study	260
Areas for focus in caretaking of leprosy sufferers	261
Recommendations for future research	263
Conclusion	264
Afterthought	264
REFERENCES	266
ANNEXURE 1: ORIENTATION TO LIFE QUESTIONNAIRE	293
ANNEXURE 2: INTERVIEW SCHEDULE	299
ANNEXURE 3: DRAWING IN JALO'S MEDICAL FILE	302

CHAPTER ONE

MAPPING OUT THE CONTEXT: AN INTRODUCTION

BACKGROUND

Leprosy (also referred to as Hansen's disease) is a chronic infectious disease, occurring worldwide (Feldman, 1998; Noble, 2001; Rakel, 2001; Yanoff, 1999). Clinical manifestations are largely restricted to areas such as the skin, eyes and peripheral nerves (AAP, 2000; Behrman, 2000; Mandell, 2000). Right from biblical times leprosy has been portrayed as a highly contagious disease, inflicted as a result of sin. Due to this perception leprosy sufferers have been severely stigmatised and isolated from the community. Perhaps no other human disease, apart from the periodic outbreaks of plague and the rise of the HIV epidemic, has provoked stronger social responses. Some authors, basing their opinion partly on misconceptions about the medical aspects of leprosy, describe this disease as the extreme in physical disfigurement and negative social consequences.

Although extensive research has been conducted on the medical aspects of leprosy, comparatively little research has been done in the sphere of the psychosocial effects of the disease. One of the few studies on this subject was conducted by Scott (2000) in South Africa. From this research it became clear that the psychosocial needs of leprosy sufferers in South Africa are similar to those of leprosy sufferers in other parts of the world. This similarity manifests itself in three ways: the necessity of self acceptance, the need for social acceptance and the need for acceptance by the community. During the study many stories of despair emerged. It became apparent that tremendous courage is required to deal with the emotional pain that accompanies leprosy and that - in order to cope with the negative psychosocial impact of the disease - sufferers need effective coping strategies. It was surprising that, without any formal psychotherapeutic intervention, some leprosy sufferers were indeed able to cope successfully with a variety

of stressors inflicted by their disease. The focus no longer seemed to be (psychologically speaking) on the pathogenesis of the disease. While the pathogenic approach is primarily concerned with the societal consequences of poor health, the focus seemed to have shifted to the origins of well-being. The researcher realised that leprosy sufferers should be assisted in coping by focusing on the salutogenesis of the disease.

The concept salutogenesis was formulated by Antonovsky (1987c) to describe “the origins of health”. With the emphasis and focus on health creation rather than disease etiology, the conceptual neologism of salutogenesis - from Latin (*salus* = health) and Greek (*genesis* = origins) - was proposed in contrast to pathogenesis (Antonovsky, 1979). Whereas the pathological orientation seeks to explain why people become ill and why they enter a given disease category, the salutogenic model disregards the fundamental dichotomy between healthy and ill people. In short, the aim of the salutogenic perspective can be summarised in the salutogenic question, “How can we explain health rather than disease?” (Antonovsky, 1987c). Thus the salutogenic question *par excellence* is: Why do some cope successfully, in spite of omnipresent stressors, and others not? The salutogenic approach is all-encompassing and investigates the life story of a person within his or her environment (Antonovsky, 1987c). As one of the earliest architects of the biopsychosocial framework and by developing his concept of salutogenesis, Antonovsky has helped to break the stranglehold of purely physical models of health (Dossey, 1994).

Antonovsky’s concept of salutogenesis had to be operationalised, however (Strümpfer, 1995). Consequently, he formulated the fulcrum of salutogenesis, which is the Sense of Coherence (SOC). The salutogenic model is based on Antonovsky’s premise that SOC is a major variable in determining the health of an individual. Individuals with a strong SOC have the ability to perceive stressors as manageable, meaningful and comprehensible. A positive outcome (of an encounter with a stressor for example, neutral or salutary health effects) is primarily dependent on the successful management of the stressor and the presence of a strong SOC. Antonovsky claimed that any

individual who has a strong, ingrained SOC in his life is less likely to succumb to microbiological and psychological pathogens than those individuals under equal life stress, but whose lives have less coherence. This study takes the theory of Antonovsky as its point of departure and focuses on explaining the effects of stress, social support and life events on the SOC of individuals suffering from leprosy.

AIM AND RATIONALE OF THE STUDY

Little research has been conducted to determine the specific coping mechanisms commonly applied by leprosy sufferers to adjust to the comprehensive psychosocial implications of this disease. This study aims, therefore, to give the participants the opportunity to tell their stories of living with a chronic illness and to express their opinion on how they are coping with leprosy. It is hoped that an understanding of the complexity of handling a chronic illness will be generated.

As indicated by the title of this study, an attempt has been made to determine how different SOC concepts manifest themselves in leprosy sufferers. The SOC conceptual framework of Antonovsky (1987c) will serve as point of departure in order to study the aforementioned.

The findings of the study may result in alternative views and treatment of leprosy. The findings may also serve as a theoretical basis for future support in the quality of life of individuals with the illness.

THE DESIGN OF THE STUDY

According to Mouton (2001), qualitative research enables the researcher to gain a deep understanding of the experiences, perceptions and beliefs of the participants. A qualitative research approach will therefore be followed in this study as it suits the aim of the research, namely to obtain an in-depth and rich understanding of the experience of

leprosy through listening to the voices of the participants. Given that the study was inductive and sought to identify whether sense of coherence (SOC) constructs played a role in how leprosy sufferers coped with the disease, in-depth interviews with and non-participant observations of participants were considered to be the most effective way of obtaining data. At the heart of the activity was a desire to understand the experience of leprosy sufferers and their perceptions about living with the disease. Although this was the honest intention of the researcher, Marshall and Rossman (1999) maintain that any researcher should carefully scrutinise the “complex interplay of our own personal biography, power and status, interactions with participants and written word” (p 67). This researcher therefore engaged in some preliminary self-reflection to uncover personal subjectivities and in an attempt to ensure theoretical sensitivity. Hence the following personal statement:

A PERSONAL STATEMENT

My earliest encounters with leprosy were the jokes about lepers which were told at school. The expression “Don’t treat me like a leper” was well-known to me. My first real encounter with leprosy was when my father joined the Leprosy Mission in 1985. I was introduced to leprosy sufferers by my father. There was a mystery attached to them when I paid my first visit to Westfort Hospital in Pretoria where leprosy sufferers were institutionalised at the time. The Leprosy Mission as an instrument in God’s hand had been apparent all along as I witnessed some leprosy sufferers’ firm faith in God. Inevitably, my own spiritual experience as a researcher would come into the equation. Another factor that might play a role in the research process is that I have moved away from my original cognitive approach in psychotherapy and have developed a keen interest in Jungian psychology. That may explain some Jungian ideas which might be articulated in the final analysis of the research results. I will, however, strive to keep an open mind and attain an eclectic research result. I intend to allow the participants’ voices to speak, but do wish to acknowledge that someone else might have told their stories in a different way and extracted different themes and conclusions.

SAMPLING AND SELECTION

The central criterion for selecting participants will be their 'assumed' ability to cope with leprosy. Five members of the Leprosy Mission who have contact with leprosy patients (from different provinces) will be requested to administer Antonovsky's Life History Questionnaire on thirty leprosy patients who (in their perception) have an assumed ability to cope. These members will mainly be tertiary trained nursing and social work personnel appointed to address the biopsychosocial needs of leprosy patients. The Life History Questionnaire will be verbally administered by these members from the Leprosy Mission. The questionnaire will be administered in English and not translated into any other language. The interviewers will make sure that the participants understand the questions. The results on these questionnaires will be compared and respondents who achieve high scores (compared to other respondents) on the questionnaire will serve as suitable participants for the main study. The members of the involved provinces will be requested to arrange interviews with the respondents.

COLLECTING THE INFORMATION

In the main study, semi-structured interviews will be conducted with the participants once they have given a short presentation of their life history. An interview schedule (Annexure 2) will be used as a guide, but the researcher will also apply psychotherapeutic conversational skills to generate in-depth information. The questions asked will be built around wide interview themes exploring SOC constructs. Care will be taken to avoid imposing too much structure on the interview, in order to prevent affecting the quality of the data (Schreiber, 2001). The participants will be given the opportunity to describe their experiences in their own narratives.

With regard to the practical execution of the study, the researcher will follow the following procedure:

- The purpose and procedures of the study will be explained to each participant. Participants will be asked to participate, and tape recordings of the interviews will be made with their consent. Each participant will then be interviewed individually. The times and duration of the interviews will be scheduled according to individual needs of the participants.
- The tape recorded interviews will be transcribed to allow for an analysis of the data.

ANALYSIS OF THE DATA

- Sense of Coherence (SOC), as well as additional emerging themes, will be identified from the transcribed interviews.
- Emerging themes will be identified from each participant's interview and illustrated with examples from his or her story.
- A comparative analysis will integrate the emerging themes and allow the practical consequences of the findings to emerge.

PRESENTATION OF THE STUDY

The study will comprise the following chapters:

Chapter 2 will highlight the medical aspects of leprosy. The physical ramifications of leprosy are an important contributing factor to the trauma patients' experience, and a detailed description of these aspects of leprosy is therefore essential.

Chapter 3 will entail a discussion of the psychosocial stressors related to a diagnosis of leprosy. It is clear that the physical difficulties which leprosy patients have to deal with are comprehensive and complex in nature. In the light of the medical aspects of the disease, it becomes clear that the psychosocial stressors which leprosy patients experience are immense.

Chapter 4 will comprise an analysis of the salutogenic model, followed by a discussion of the salutogenic constructs. This background will substantiate the selection of specific salutogenic constructs, whereafter each construct, namely hardiness, locus of control, self-efficacy, potency and learned resourcefulness, will be analysed. This chapter will conclude with a discussion of the social implications of the SOC phenomenon, as well as the spiritual dimension of SOC.

In **Chapter 5** the research methodology applied in this study will be discussed. Qualitative research is regarded as the appropriate research methodology to obtain in-depth and enriched information. The nature of qualitative research, including a description of data gathering methods such as semi-structured interviews and non-participant observations, will be the focus of this chapter.

Chapter 6 will consist of a presentation of each participant's story. The story will then be analysed and examples from the story will be provided to indicate how the SOC themes are revealed in the participant's coping. Related emergent themes in each participant's handling of leprosy will also be identified.

Chapter 7 will contain the comparative analysis. In the kaleidoscope of stories, each person's story will retain its own unique nature, but an attempt will be made to synchronise the interfaces to create an integrated picture. Both unique and shared ways of coping revealed in the participants' stories will be discussed in this chapter.

Chapter 8 will conclude this study. In this chapter a summary of the coping themes identified in the participants' stories will be provided. Furthermore, the study will be assessed in terms of its strengths and limitations. The researcher will conclude with suggestions for caretakers of leprosy sufferers, as well as proposals for future research.

CONCLUSION

Very little consideration has been given to the way in which leprosy sufferers deal with their disease. The main focus of existing research on leprosy seems to be on the medical aspects and not particularly on the psychosocial aspects. This study will therefore attempt to address this shortcoming by giving leprosy sufferers the opportunity to tell their stories and, in so doing, to reveal their opinions of how they are coping with the disease.

CHAPTER TWO

LEPROSY – THE NON-EXISTING ILLNESS?

INTRODUCTION

From the description of leprosy in chapter one, it becomes clear that the psychosocial stressors with which the patients struggle, are vast. In order to fully understand the psychosocial nature of the disease, it is vital to establish a clear picture of the comprehensive implications of leprosy. Photographs by Jacyk (1986) in this chapter show the different types of leprosy. The physical ramifications are an important contributing factor to the trauma which patients experience. A detailed description of the medical aspects of leprosy follows.

LEPROSY DEFINED

Leprosy (also referred to as Hansen's disease) is a chronic infectious disease, which occurs worldwide (Feldman, 1998; Noble, 2001; Rakel, 2001; Yanoff, 1999). The agent, *Mycobacterium leprae* (*M. leprae*), affects primarily the skin and the peripheral nervous system. To a lesser extent the upper respiratory system, eyes, liver and testes are infected, too (Behrman, 2000; Cotran, 1999; Noble, 2001). Leprosy is also associated with peripheral arthritis, which onsets months to years after the commencement of the infection (Nadeau, 2002; Ruddy, 2001).

The distinction between leprosy and other rheumatoid diseases is based on the following characteristics of leprosy: presence of nodules (knots in tissue), male preponderance and complete resolution with anti-leprosy therapy (Ruddy, 2001). The diagnosis of leprosy is founded on the manifestation of acid-fast organisms in skin biopsies and clinical manifestations (Belsito, 2000; Cotran, 1999; Noble, 2001), which will be discussed in the following section.

CLINICAL MANIFESTATIONS OF LEPROSY

Although only one organism, namely *M. leprae*, causes the disease, leprosy has a wide range of clinical manifestations determined by the host's response to the infecting organism (Middleton, 1998). As previously mentioned, clinical manifestations are largely restricted to the skin, upper respiratory system, eyes, testes and peripheral nerves (AAP, 2000; Behrman, 2000; Mandell, 2000).

A variety of cutaneous lesions on the skin and a loss of nerve conduction are generally associated with leprosy (Cotran, 1999; Goldman, 2000; Noble, 2001; Rakel, 2001). Clinically, these lesions must be distinguished from tropical ulcers, syphilis and deep fungal infections (Behrman, 2000; Lemons-Estes, Neafie & Meyers, 1999). According to Noble (2001) and Cotran (1999), skin lesions of leprosy preferably appear on the coolest parts of the skin for example elbows, knees, buttocks and face (especially the cheek, nose and brow). However, the midline of the back is normally spared.

Most of the serious consequences of leprosy are a result of the agent's unique tropism for peripheral nerves. Both major nerve trunks and microscopic dermal nerves may be affected in leprosy patients. The most common nerve trunk impairment being the ulnar nerve at the elbow, perhaps owing to its superficial, cool site and the stretch imposed by elbow extension (Mandell, 2000; Rakel, 2001). Damage to this area results in clawing of the fourth and fifth fingers and loss of sensation of the hand (Steiner, Salvadori, Concepcion, Gimino, Kamat, Sibilila & Fink, 2001). Median nerve dysfunction is less usual and leads to an inability to oppose the thumb and grasp and hold objects. Radial nerve dysfunction is unusual in leprosy but, when present, results in wrist drop. Peroneal nerve dysfunction leads to foot drop (Mandell, 2000). Small nerve fibers are most usually functionally impaired, resulting in loss of fine touch, pain and hot and cold sensation (Mandell, 2000; Yanoff, 1999).

Among infectious diseases, leprosy is a major cause of permanent physical disability in the world (Rakel, 2001). Marked anaesthesia (lack of touch or pain sensation) causes delayed detection of injury, with consequent burns, wounds and ulceration (Juhl, 1998; Mandell, 2000; Requena & Yus, 2001; Steiner *et al.*, 2001). Serious disfigurement as a result of anesthesia and bone absorption, as well as accompanied loss of fingers or limbs, may result in permanent disability (Behrman, 2000; Mandell, 2000).

Infections of the upper respiratory system are characterised by the appearance of nodules on the mucosal membranes, tongue and palate (Schuster, 1999). The initial lesions are swellings on the lips that become flat nodules. Later the tongue may develop lesions, which may range from mild glossitis to nodules on the whole tongue or areas of the tongue. In later phases lesions may appear on the uvula, the hard and the soft palates. Palatal perforation may also result. As palatal damage progresses, facial paralysis occurs and is accompanied by a loss of facial expression (Schuster, 1999). Nasal collapse may, in addition to facial paralysis, lead to severe facial deformity (Mandell, 2000).

Paralysis of facial nerve may result in lid abnormalities, which can develop into corneal damage (Yanoff, 1999). Corneal insensitivity may lead to “beaded” corneal nerves, which may develop into secondary eye infection and scarring (Mandell, 2000; Yanoff, 1999). In lepromatous leprosy (discussed later), the loss of eyebrows and eyelashes are common (Noble, 2001). Furthermore, the agent invades the anterior chamber of the eye and this may result in glaucoma and cataract formation (Mandell, 2000), which may eventually lead to loss of vision. Three to seven percent of leprosy sufferers are blind due to the destruction of the autonomic nerve fibres that supply the eye (Yanoff, 1999).

Although liver dysfunction may be caused by this disease (Wilson, 1998), the major organ found functionally impaired is the kidney, leading at times to renal failure and the need for dialysis. However, the kidneys are seldom primarily affected by leprosy (Mandell, 2000).

In lepromatous leprosy, bacilli may invade the testes, which usually leads to low sperm counts and testosterone levels, resulting in infertility or impotence, or both (Khorram, Patrizio, Swerdloff & Wang, 2001; Mandell, 2000; Nehra & Moreland, 2001).

TYPES OF LEPROSY

The identification of the type of leprosy is important in predicting disease complications, reaction states likely to be encountered, and intensity and duration of required chemotherapy (Mandell, 2000). The clinical syndromes of leprosy illustrate a spectrum that reflects the cellular immune response to *M leprae*. In this section the characteristics of the different forms of leprosy are discussed (AAP, 2000). Besides the discussion of the polar types of leprosy, called tuberculoid and lepromatous leprosy, a third form, which lies between these two opposite forms of leprosy, named borderline leprosy (with its three subdivisions) will also be highlighted. The earliest noticeable form of leprosy is called indeterminate leprosy (Behrman, 2000). This type of leprosy will henceforth be discussed.

Indeterminate Leprosy (IL)

Results obtained from skin testing suggest that up to 90% of people infected with leprosy develop immunity without ever manifesting the disease clinically. Most of the remaining sufferers, after an incubation period averaging three to five years, develop typical skin lesions of indeterminate leprosy. As mentioned earlier, this is the earliest clinically noticeable form of leprosy (Behrman, 2000). With indeterminate leprosy, a single hypopigmented macule (stain like mark on the skin), two to four centimeters in diameter, with a poorly defined border, is located on the leprosy sufferer's skin. Anesthesia of the macule is minimal or absent, especially if the macule is on the face. In 50 to 75% of patients with indeterminate leprosy, the lesions recover spontaneously. The remainder of the patients may develop either tuberculoid, borderline or lepromatous leprosy

(Behrman, 2000). Most patients with advanced leprosy have initially contracted indeterminate leprosy.



Image 2.1
Indeterminate Leprosy (IL)

Tuberculoid Leprosy (TL)

Tuberculoid leprosy is signified by the fact that the disease pursues an extremely slow course to develop fully. Taken into consideration that it might take decades for tuberculoid leprosy to emerge, most patients die with leprosy rather than of it (Cotran, 1999). With TL, the development of a moderate to intense immune response is characteristic. Such response leads to reduced numbers of *M. leprae* in localised cutaneous lesions of tuberculoid patients (Cotran, 1999; Goldman, 2000; Noble, 2001). Few bacilli found in the tuberculoid form (paucibacillary / PB) normally leads to the formation of a single large (often over 10 cm in diameter) visible lesion (Behrman, 2000). Initially the lesion is flat and red, but later enlarges and develops irregular shapes (Cotran, 1999). The interior of the lesion is flat, hypopigmented (lacking pigmentation)

and anesthetic (Behrman, 2000; Goldman, 2000; Noble, 2001; Walsh, 1998). Although not very often, there may develop as many as four lesions on the body of a tuberculoid patient (Behrman, 2000).

Without treatment, the skin lesion tends to enlarge slowly, but documented instances of spontaneous resolution exist. Loss of hair follicles, sweat glands, cutaneous nerve receptors and sensation in the centre of the lesion are irreversible (Behrman, 2000). *M. leprae* does not only affect cutaneous nerve receptors, but nerves leading to the ear, elbow and knee may be palpably swollen. Nerve degeneration leads to skin anesthetics and skin and muscle atrophy that render the patient liable to trauma of the affected parts (Cotran, 1999). Almost any region of the skin may be affected except for the warmer regions of the scalp, axilla and perineum. Furthermore, damage to the nervous system (Cotran, 1999), as well as progressive absorption of bone (Juhl, 1998), is frequent in TL.



Image 2.2
Tuberculoid Leprosy (TL)

Borderline Leprosy

Borderline leprosy is subdivided into three classes that lie between the tuberculoid and lepromatous poles on the clinical spectrum (Behrman, 2000). These classes are borderline tuberculoid (BT), borderline (BB) and borderline lepromatous (BL) (Behrman, 2000).



Image 2.3
Borderline Tuberculoid Leprosy (BT)

In the case of BT, the emerging lesions are larger in number, but smaller in size than in tuberculoid leprosy. The skin displays an array of hypopigmented lesions involving primarily the trunk, extremities and face. Often small satellite lesions form around older lesions. In most instances, the margins of BT lesions are not clearly visible (Goldman, 2000).

BB is characterized by abundant lesions, which are generally heterogeneous in appearance. The borders of the lesions are, as in the case of BT, poorly defined. Even though hypesthesia (diminished sensitivity to stimulation) is familiar in BB, anesthesia has



Image 2.4
Borderline Leprosy (BB)

also been recorded. Mild to moderate nerve thickening is characteristic, but severe muscle wasting and neuropathy are unusual (Behrman, 2000).

With regard to BL, a vast number of asymmetrical lesions, which are heterogeneous in appearance, form the visible pattern of the disease. Macules, papules (small, circumscribed, solid elevations on the skin) and nodules may all coexist in BL. Anesthesia is mild and individual lesions are small compared to lesions in lepromatous cases. The initial response to treatment often takes the form of a dramatic flattening in nodules within two to three months (Behrman, 2000).

Lepromatous Leprosy (LL)

Patients who are unable to develop an immune response to *M. leprae* may suffer from widely distributed skin lesions of the lepromatous state (Goldman, 2000; Yanoff, 1999). In most instances, the lesions are countless, often confluent and symmetric (Cotran, 1999; Goldman, 2000). During the initial stages of the disease, the only visible signs of

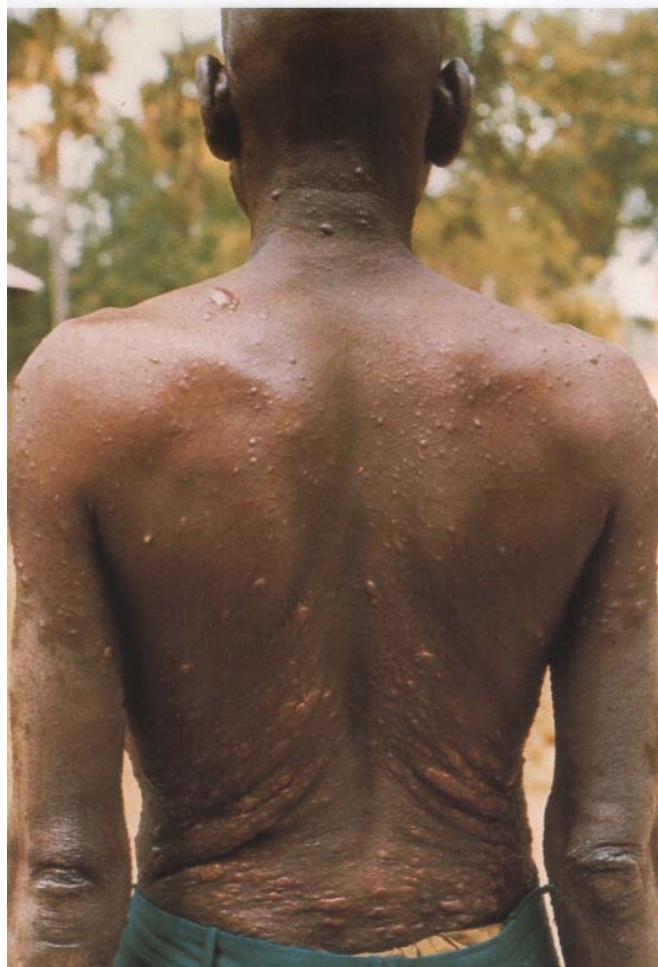


Image 2.5
Borderline Lepromatous Leprosy (BL)

these usually are vague macules or uniform skin infiltrations without observable lesions (Behrman, 2000). In these cases, the skin tends to look shiny and “full”, as if the dermis is expanded with macrophages containing bacilli (Middleton, 1998). The dermis is crowded with vast numbers of bacilli (multibacillary / MB) in the lepromatous form. As the disease develops, the lesions become increasingly papular and nodular (Goldman, 2000; Noble, 2001). Anesthesia of the lesions does not occur or is mild (Behrman, 2000). The lesions are particularly noticeable on the ears, eyebrows and face, creating a lion-like appearance, called “leonine facies” (Cotran, 1999; Goldman, 2000; Noble, 2001).



Image 2.6
Leonine facies

Eyebrow loss is common and a saddle nose deformity may result. Blindness, a loss of teeth and a loss of fingers could occur. Lesions in the nose may cause chronic inflammation and bacilli-laden discharge (Cotran, 1999). Nerve damage in LL is relatively slow advancing, but is eventually severe, diffuse and could lead to a sensory polyneuropathy. Rigid, swollen nerves are palpable in many locations.

Testicular infiltration, leading to infertility, is frequently found in adults, but does not often happen to children (Behrman, 2000). Testicular atrophy develops in 10 to 20% of men with LL as a result of direct invasion of the tissue by the bacilli (Wilson, 1998). Bacilli are



Image 2.7
Lepromatous Leprosy (LL)

found in most of the internal organs other than the vital organs and the central nervous system. The fact that the core temperature of the vital organs and the central nervous system is too high for growth of *M leprae*, seems to be the reason for the absence of bacilli in these areas (Cotran, 1999). In the organs where bacilli do settle, tissue damage is seldom found.

The initial reaction to treatment of LL is often encouraging in the sense that results are dramatic, but such improvement is frequently followed by a two to four year period of very slow betterment. The reason for such delayed recuperation may be attributed to the specific anergy which the leprosy bacillus endures in spite of treatment, thus making the patient theoretically defenseless against a relapse if even a single viable bacillus remains at the end of therapy. Due to the presence of diffuse, parasite-filled lesions, patients suffering from LL are more infectious when compared to TL patients (Cotran, 1999).

REACTIONAL STATES

According to Behrman (2000), severe clinical exacerbations are common in leprosy and reflect abrupt changes in the host-parasite immunologic balance. Although reactional states usually occur in the absence of treatment, they are especially frequent during the initial years of therapy. Behrman (2000) claims that up to 50% of patients receiving efficient chemotherapy can develop reactions and unless properly treated, they will manifest with crippling deformities. Three major variants of responses can be identified, namely reversal reactions, erythema nodosum leprosum reactions and Lucio's reactions.

Reversal reactions (also referred to as Type 1 reactions) are observed especially in BL. Acute sensitivity and swelling at the area of existing cutaneous and neural lesions, as well as the development of new lesions, are the major manifestations. New or existing skin lesions often ulcerate to leave hideous scars. Irreversible nerve injury (anesthesia, facial paralysis, claw hand and footdrop) may develop if not treated immediately. The initiating event is the sudden increase in effective cell-mediated immunity in response to *M. leprae* antigens after rapid killing of bacilli (Behrman, 2000).

Erythema nodosum leprosum reactions (Type 2 reactions) are life threatening and appear in most cases of LL and in 25 to 40% of borderline lepromatous cases (Behrman, 2000). Type 2 reactions are typified by tender, erythematous nodules associated with fever (Behrman, 2000; Cotran, 1999; Noble, 2001). Type 2 reactions may be trivial or critical and unremitting, leading to extensive morbidity (Mandell, 2000).

Lucio's reactions are also identified in LL, and is typified by the presence of angular dermal ulcers as a result of artheritis (Noble, 2001). Lucio's reactions are often fatal, usually a result of secondary bacterial infection (Mandell, 2000).

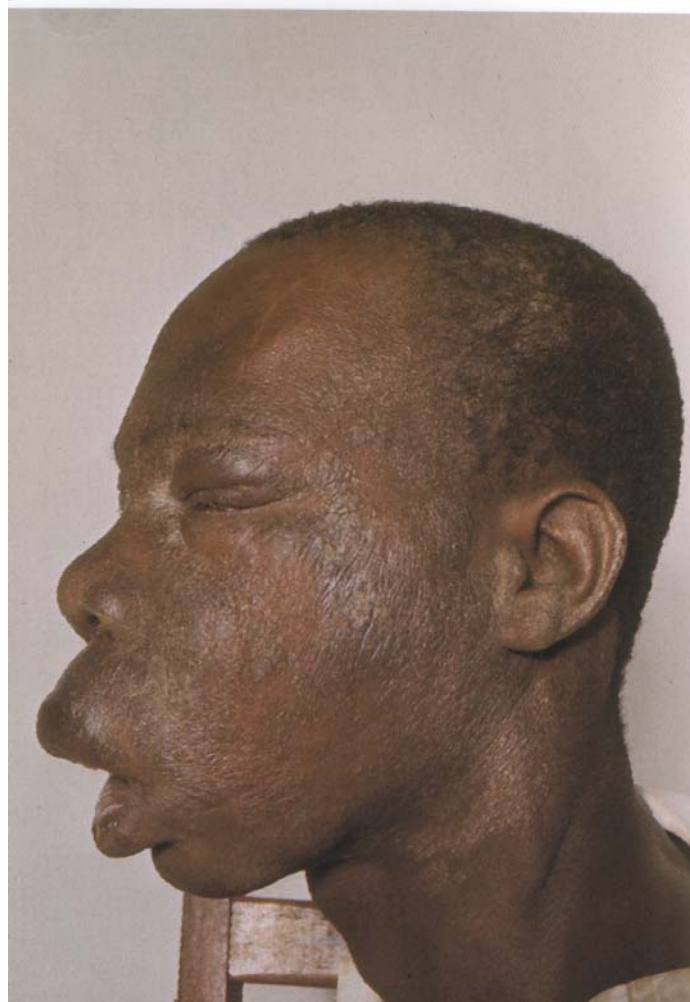


Image 2.8
Reversal Reaction

TRANSMISSION OF LEPROSY

Although the mode of transmission of leprosy remains uncertain, the American Academy of Paediatrics (AAP) (2000) suggested that the major method of

transmission seems to be contact with humans who have untreated or drug-resistant leprosy of one of the borderline types or the lepromatous type of leprosy. Investigators generally agree that the nose is the primary site of inoculation (Mandell, 2000; Yanoff, 1999) and that *M leprae* in the above-mentioned patients is spread from person to person primarily as a nasal droplet infection (Rakel, 2001; Steiner *et al.*, 2001). It seems as if people become contaminated by nasal droplet infection when they are exposed to patients who discharge large numbers of *M. leprae* when they cough or sneeze. The number of bacilli in a sneeze from a patient with untreated lepromatous leprosy is similar in magnitude to the number of bacilli in a cough from patients with a serious disease like untreated pulmonary tuberculosis. *M. leprae* remains potent, given that bacilli recovered from dry nasal discharges retain some viability for up to seven to ten days. A greater viability of bacilli occurs under conditions of high humidity (Goldman, 2000).

A long duration of exposure to leprosy patients, such as those accompanied with household contact may increase the possibility of transmission of leprosy (AAP, 2000). Transmission of leprosy from an untreated, infected mother to an infant is not uncommon. Taken into consideration that up to 20% of children born to mothers with leprosy may experience leprosy by puberty (Kroumpouzou & Cohen, 2001; Zhu & Stiller, 2001), as well as the occurrence of leprosy in infants as young as three months of age, it can be assumed that in utero transmission may take place (Behrman, 2000). The incidence of the disease within a household containing an infected lepromatous patient may be four to eight times that of the general population (Goldman, 2000). According to Van Beers (1999), the estimated risk of contracting leprosy is approximately four times higher if a person is exposed to a patient in a neighbouring house.

On the other hand, multibacillary leprosy is infectious to such an extent that the likelihood of contracting the disease from a multibacillary patient in a neighbouring house is similar to the possibility of contracting the disease from a paucibacillary patient in the same household. However, according to the AAP (2000), between 70 to 80% of infected patients in endemic areas do not have a history of household

contact or other exposure with a known or suspected case of leprosy, implying the possibility of other sources of infection. Mandell (2000) also puts less emphasis on the importance of household contact as a means of transmission by speculating that residence in an endemic country imposes a greater risk of disease than that posed to household contacts in non-endemic areas.

Nevertheless, accumulated clinical evidence indicates that disease transmission takes place only after years of exposure (Goldman, 2000). The number of exposed persons far exceeds those who actually develop leprosy (Lemaster and Roche, 2000). It can thus be accepted that chances are slight to contract leprosy by having limited contact with leprosy patients. Therefore, the AAP (2000) indicates that little likelihood of transmission is present in a hospital setting. Seemingly, patients are generally hospitalised with a minimum of precautions (AAP, 2000). Although researchers exempt the nose as the primary site of inoculation, a variety of other possible transmission modes are mentioned.

Some transmission modes appear to be considered as more probable modes of transmission when compared to others. Skin-to-skin contact, for example, formerly thought to be an important transmission mode, is not likely to be the general route of infection. However, trauma, secondary infection and certain lepromatous reactions may result in exfoliation of the epidermis, thereby allowing for a direct route of egress of organisms (Mandell, 2000). Such direct inoculation through for example trauma and puncture wounds might create an initial concentration of bacilli in a person's body (Goldman, 2000).

Speculation persists with regard to non-human modes of transmission. Presently, mounting evidence from several sources suggests that leprosy may be transmitted by soil. Attempting to prove the possibility of transmission of leprosy by soil, Mandell (2000) indicates that:

- The *M. leprae* specific phenolic glycolipid 1 (PGL-1) has been found in soil;
- Leprosy is restricted to rural areas where the wearing of shoes is uncommon

and the contraction of leprosy by means of feet-soil contact is highly likely; and

- Direct dermal inoculation, such as in tattoo parlors, has been associated with transmission and may be applicable where a patient had direct contact with soil infected with *M. leprae*.

Apparently, it is also possible that patients may contract leprosy by having contact with animals. A major source of infection of leprosy sufferers seems to be nine-banded armadillos living in Texas, Louisiana and Mexico (Behrman, 2000; Mandell, 2000). Of 740 cases of US native-born leprosy patients reported between 1952 and 1980 that 56% were born in Texas, while Louisiana-born patients accounted for 14% and Californian sufferers made up 4% (Bruce, Ellner, Rubin, Schroeder, Williams & Wolf, 2000). The high incidence of leprosy in these areas could be attributed to the greater likelihood of exposure to Hansen's disease patients from Mexico. However, another explanation for this high incidence of leprosy in this region could be armadillo exposure.

Although armadillos are naturally infected with *M. leprae*, the origin of these infections in wild armadillos remains uncertain. The hypothesis that environmental infection may have inadvertently occurred during experimental infections has largely been disproved. Several other proposals exist, for example, Bruce *et al.* (2000), suggests that contaminated soil or vegetation may play a role. Insects and earthworms living in infected soil have also been considered as means of infection since much of the armadillos' diet consists of insects and earthworms. Other nature-elements such as thorn pricks have also been indicated as a possible medium of transmission of leprosy in the wild armadillo. In addition, the possibility exists that armadillos are infected by humans as well as human-related elements (Bruce *et. al.*, 2000). Apparently, armadillos and human beings are ideal agents for reciprocal transference of this disease. *M. leprae* grows rapidly at 32 to 34 degrees celcius, which is the temperature of the human skin and the core temperature of armadillos (Cotran, 1999). Bruce *et al.* (2000) suggest that disposed contaminated clothing, dressings or body remains of infected humans seem to be a possible role player in

transmission of the disease to the wild armadillo. After leprosy had initially been introduced into the armadillo population by human beings, its continuation might have taken place by animal-to-animal transfer, for example, transmission from mother to offspring is not impossible.

However, the transfer of leprosy from the armadillo to human beings is of much more interest to man than the contamination of armadillos by human beings. Since the armadillo has been established as a reservoir of leprosy, the possibility of the animal playing a role in this disease has been investigated. In 1977, Filice, Greenberg and Fraser evaluated the armadillo exposure of 19 leprosy patients in Louisiana with age-and sex-matched controls. They concluded that there is no relation between armadillo contact and leprosy in their patient population. However, in 1981, a leprosy sufferer was reported who had lived most of his life in Texas as a rancher and had a significant history of hunting, trapping and eating armadillos. Six additional leprosy patients, all with intensive and long-term armadillo exposure were subsequently reported. Bruce *et al.* (2000) portrayed six isolated residents of Northern Louisiana who lived in “an essentially nonendemic area” and developed leprosy. The patients apparently lacked “risk factors” such as contact with leprosy patients, travelling to endemic areas and residence in an endemic area. Four of the six had a history of direct contact with armadillos and all six had had indirect contact. The possibility of these patients being infected by armadillos is substantiated by a survey of armadillos from different areas in Louisiana, which has shown that the rate of infectivity of armadillos in northern Louisiana is as high as 30%. Further studies are, however, needed to prove direct transmission of *M. leprae* from armadillos to human beings.

Other animal sources such as the chimpanzee, the sooty mangabey monkey, a New World monkey, and insects, have also been identified as possible agents (Rakel, 2001). In both armadillos and monkeys it takes time before they become highly infected. The injected bacilli need between 18 to 24 months to reach high numbers (Goldman, 2000). Insect vectors, such as mosquitoes, may also play a role in disease transmission (Behrman, 2000).

When compared to other human diseases, these “animal-inflicted” infections are quite uncommon (Goldman, 2000). However, more research is necessary to verify transmission from the mentioned animals and insects to humans (Rakel, 2001).

SUSCEPTIBILITY

Leprosy occurs in individuals of all ages (Behrman, 2000). Infections in infants are, however, extremely rare and apparently the disease appears more frequently in, for example, young adults. A higher incidence of leprosy in young adults may be related to leprosy’s long incubation period (Goldman, 2000; Mandell, 2000).

Pregnancy may activate the onset of leprosy in mothers probably because of changes in cell-mediation in their bodies. The first appearance of leprosy, the reactivation of the disease and a relapse in “cured” patients appear to occur particularly in the third trimester of pregnancy (Kroumpouzou & Cohen, 2001; Zhu & Stiller, 2001). In cases where mothers have contracted leprosy, a high incidence of infant mortality and low birth weights amongst newborns seem to prevail (Kroumpouzou & Cohen, 2001).

EPIDEMIOLOGY

The introduction of multidrug therapy (MDT) by the World Health Organisation (WHO) in 1982, has led to a steady decline in the prevalence of leprosy (Behrman, 2000; McDougall, 1998). The implementation of a worldwide disease-specific programme has led to an 85% reduction of leprosy in the last 15 years.

The WHO aimed to eliminate leprosy as a public health problem by 2000 (Fine & Warndorpf, 1997). However, this ideal has not been attained. In the year 2000, an estimated six million persons were still suffering from leprosy, of which three million were still untreated (Mandell, 2000). Furthermore, according to the WHO, between two and three million individuals are permanently disabled because of leprosy. For many of these patients, the WHO programme failed to reach them in time with MDT

(Rakel, 2001).

Although the incidence of leprosy appears to have declined in some countries, there is no convincing evidence that this is the case on a global scale (Fine & Warndorpf, 1997). Seemingly, the problem lies with the identification of new and existent leprosy cases and subsequently, there may globally be many more cases compared to what leprosy incident figures suggest. Part of the problem appears to be the fact that diagnosis of leprosy is not always considered (Marlowe & Lockwood, 2001). These authors critically comment that the unsatisfactory decline of leprosy in some countries is likely to be at least partly attributable to amalgamation of leprosy control programmes into general health services. A great possibility exists that an increase in disability in new leprosy cases may prevail as long as leprosy diagnoses are left to general health staff who increasingly recognise leprosy only when the patient presents with a classic disability. If a situation continues where visible disabilities are the first and foremost indications of leprosy, many early cases will not be diagnosed (Fine & Warndorpf, 1997). Furthermore, these authors claim that an efficient method to make a disease disappear is to stop looking for it. Some justification for health workers not diagnosing leprosy is that, partly attributable to leprosy eradication programmes, leprosy has (in most countries where the occurrence of leprosy was an almost constant fear) become a forgotten epidemic, unrecognised when leprosy sufferers report themselves to a health centre (Ryan, 2000). However, Smith (1997) is much more optimistic than the above-mentioned authors by estimating that the target prevalence of 1 leprosy case in 10 000 people worldwide is undoubtedly an attainable goal.

In addition, Rakel (2001) substantiates the possibility of leprosy eradication by stating that of 122 countries where leprosy was perceived as a public health problem (defined as having a prevalence of more than one case per 10 000 population) in 1985, thus far 98 countries have reached the elimination target with the implementation of short term Multi-Drug Therapy (MDT) (Rakel, 2001). However, according to Mandell (2000) it should be remembered that with the introduction of effective short-course chemotherapy for pulmonary tuberculosis, a similar optimism

concerning worldwide control of tuberculosis emanated in the 1970s. However, that optimism has been shattered in the past decade by an increased incidence of tuberculosis in the United States. Although the worldwide number of registered leprosy cases does not suggest that leprosy is, unlike tuberculosis, no longer a public health problem in many areas of the world, there remains concern about the number of cases added each year. In 1997, 658 000 new cases were registered (Zhu & Stiller, 2001). During 1998, the detection rate was 13.5 per 100 000 population, the highest level ever recorded. Presumably, this increase in leprosy numbers can be attributed to enhanced and intensified efforts in case detection in all endemic countries. This substantial increase in leprosy numbers emphasises the existence of cases remaining "hidden" in the community for various reasons, amongst others, the stigma attached to the disease and accompanied resistance to report for treatment, as well as limited accessibility of health services in many endemic countries (Rakel, 2001).

Factors such as socio-economic conditions (including body exposure to the environment) and the availability, as well as the nature of health care, may all play a role in the transmission of the disease. Leprosy is normally associated with poverty and rural residence. In cases where many people reside in one apartment, the possibility of droplet infection may be increased. India, with a population of one billion, is possibly a perfect example where factors such as overcrowding and insufficient health care have led to a situation where leprosy is still not under control in several states of this country. India accounts for 62% of all global cases and has a high percentage of newly detected cases yearly (McDougall, 1997). Special measures are taken in India to prevent this disease, for example, aspirant dermatologists have to take higher qualifications in leprosy (Ryan, 2000). In spite of special measures, the control problem of leprosy in this country can partly be attributed to the reluctance of most urban practitioners to provide sufficient health care (Ryan, 2000). India is one of the 16 major endemic countries which host more than 95% of the world's leprosy sufferers.

These 16 countries include African, South-East Asian, as well as Central and South American countries (Behrman, 2000; Yanoff, 1999). However, leprosy also occurs in the colder climates of Tibet, Korea and Siberia (Goldman, 2000). Leprosy is almost absent from Canada, Northern and Western Europe and the United States of America (USA). The USA, with a total of about 7000 leprosy sufferers, accommodates patients who are mostly immigrants from Mexico, South-east Asia, the Philippines and the Caribbean (Behrman, 2000; Mandell, 2000). There is an annual incidence of 100 to 200 newly diagnosed patients in the USA. However, with international travel, leprosy can be found anywhere (Zhu & Stiller, 2001). Evidently, there is a concentration of leprosy in specific areas in the world, nevertheless, the distribution of leprosy within endemic countries is very non-homogeneous, and even neighbouring villages may have striking differences in disease prevalence (Mandell, 2000).

The incidence of polar types of leprosy also varies widely in different populations. In India and Africa, 90% of patients are tuberculoid; in South-east Asia 50% are lepromatous and 50% tuberculoid, whereas in Mexico 90% are lepromatous. Clarification with regard to whether these differences are a result of hereditary predisposition, prior mycobacterial contact and consequent immunity, or even route of transmission, must still be found (Mandell, 2000).

TREATMENT OF LEPROSY

Significant of *M. leprae*, is its persistence to survive in an organism for many years. The long incubation period (especially in lepromatous cases as compared to tuberculoid cases) of four to six years can be attributed to the exceedingly slow multiplication of *M. leprae* (AAP, 2000; Behrman, 2000; Steiner *et al.*, 2001). This has mandated prolonged chemotherapy for leprosy patients to prevent relapse.

Since 1945, chemotherapy for leprosy mainly consisted of a drug called diaminodiphenylsulfone (dapsone) (Zhu & Stiller, 2001). Previously, the severe lepromatous form of leprosy, perceived as the most bacilliferous of human diseases,

was treated primarily and indefinitely by dapsone monotherapy. Dapsone cured thousands of patients with lepromatous and other types of leprosy, and advanced the termination of bacilli in endemic communities (McDougall, 1997). However, because of the single intake of dapsone (referred to as monotherapy), resistance of leprosy bacilli has become a widespread problem (Behrman, 2000; Ji, 1998; Mandell, 2000). To date, researchers have not been successful in identifying the molecular basis of dapsone resistance (Brennan, 1999). As a result, adjustments with regard to the therapy of leprosy have been made and subsequently, the majority of patients now receive MDT (Multi-Drug Therapy), which was introduced in 1982 (Goldman, 2000). Another major consideration for the application of MDT, besides bacilli resistance with dapsone, is the possible shortening of the duration of therapy since MDT has proved to be more effective than dapsone monotherapy in terms of faster clinical response, faster reduction of viability and lower rates of late complications like relapses (AAP, 2000; Katoch, 1998).

The principal agents used in therapeutic multidrug regimens are dapsone, rifampin and clofazimine (Levine & Paniker, 2001; Rakel, 2001; Steiner *et al.*, 2001; Yanoff, 1999). Rifampin should be given with dapsone for one year for paucibacillary (indeterminate, tuberculoid and borderline tuberculoid) cases, with close follow-up to detect relapses. Behrman (2000) alleges that rifampin is the mycobactericidal drug, which results in the most rapid treatment for *M. leprae*, achieving excellent levels inside cells, where most bacilli inhabit. Furthermore, resistance to rifampin has seldom been reported but the extensive use of rifampin has been limited by the fact that this drug is rather expensive (Behrman, 2000).

Clofazimine should be applied for multibacillary (borderline, borderline lepromatous and lepromatous) disease and continued for at least two years (AAP, 2000). Clofazimine is specifically useful in cases of dapsone resistance or when recurrent states have developed.

The use of the above-mentioned drugs may lead to side effects. For example, the intake of clofazimine may be accompanied by a dry mouth and skin, as well as life-

threatening and often irreversible gastrointestinal symptoms such as abdominal pain, diarrhea, vomiting, nausea, anorexia and weight loss (Parizhskaya, Youssef, Di Lorenzo & Goyal, 2001). Another side-effect of clofazimine may be a sudden, overexuberant immunologic response (“upgrading of immunity”), leading to irreversible nerve damage on a hypersensitivity basis (Steiner *et al.*, 2001). Skin pigmentation is quite familiar, being the result of drug accumulation and producing red-brown to nearly black discoloration, especially in dark-skinned persons (Mandell, 2000). This pigmentation clears entirely within six to twelve months after treatment is terminated (Rakel, 2001), but often results in discontinuation or poor compliance with medical treatment (Behrman, 2000).

The use of rifampin may introduce symptoms like flu, rash and hypertension (Martinez, Collazos & Mayo, 1999). According to Behrman (2000), Hepatitis is the most frequent side effect of the usage of rifampin, which necessitates discontinuance of medical treatment.

Mandell (2000) suggests that the intake of dapsone may lead to symptoms such as fever, jaundice and dermatitis.

Thalidomide is effective in the treatment of erythema nodosum leprosum (Noble, 2001). This drug is absolutely contra indicated in pregnancy, since the composition of the drug may lead to detrimental effects for the fetus (Behrman, 2000).

An intensified search for alternative therapeutic agents emanated, not only because of the abovementioned side effects, but also resulting from the increasing incidence of drug-resistant *M. leprae*. Furthermore, health professionals feel that the duration of MDT is still too long, especially in areas where the health infrastructure is poor or accessibility is difficult (Ji, 1998).

The executive report of the 7th WHO (World Health Organization) Expert Committee on Leprosy declared that the Committee considered a single dose rifampicin, ofloxacin and minocycline (ROM) an acceptable and cost-effective regimen for the

treatment of single skin lesion PB leprosy (Lockwood, 1997). If ROM is to be incorporated into treatment schedules, then it is important that fieldworkers (who are responsible for the identification and treatment of new leprosy cases) follow effective practice guidelines. It is for example critical that all patients should be examined carefully to ensure that there indeed is only a single lesion before medication is applied (Lockwood, 1997).

Immunotherapy with Mycobacterium w (M.w.) is a regimen that has also been mentioned as an alternative treatment possibility. The rationale for the implementation of this regimen is that it may boost cell-mediated immunity and therefore lead to increased clearance of bacilli (AAP, 2000; Whitty, 1998). Given that overall bacteriological cure in multibacillary leprosy is already close to 100% with conventional treatment (even in field conditions), it is unlikely to be significantly improved by immunotherapy (Whitty, 1998). If immunotherapy does initiate the functioning of the cell-mediated immune system, identifying and destroying the bacilli earlier than conventional treatment, it may hasten bacterial clearance, but at the risk of causing a higher incidence of immune-mediated reactions. These reactions can be very unpleasant and potentially cause lifelong disability. Although some clinicians hope that, with continuous research, immunotherapy may provide an answer to the successful treatment of multibacillary leprosy, the effectivity of this regimen has, however, not been proven as yet (Whitty, 1998). Given the wide variety of treatment regimens for leprosy with their possible detrimental side effects, it can be assumed that the treatment of leprosy should be considered a highly specialised field, supervised by an expert.

Despite the wide variety of drug combinations for the treatment of leprosy, the MDT method generally appears to be most effective in the treatment of leprosy patients. Data collected by the WHO from several countries on cohorts of patients completing the recommended MDT method between 1981 and 1993, have presented exceptionally favourable results in the treatment of leprosy (Behrman, 2000). Of a total of 20 141 multibacillary patients and 51 553 paucibacillary patients monitored over nine years, cumulative relapse rates were 0.74% and 1.09%, respectively. In

comparison, among multibacillary patients who were subjected to dapsone monotherapy, the expected relapse rate was between 10 to 20%. Therefore, in 1993, the WHO study group on chemotherapy of leprosy restated support for the MDT regimen (Behrman, 2000). Their vote of confidence had been substantiated by the fact that by 1997, more than 84 million leprosy patients had been cured by MDT (Ji, 1998).

In South Africa the Leprosy Mission is actively involved in the care and rehabilitation of approximately 2 500 people living with leprosy. Between forty and sixty new cases of leprosy are identified, treated and rehabilitated annually (T. de Villiers, personal communication, 3 June 2006). Leprosy cases have been declining in South Africa, but officials expect a slight increase as immigrants from neighbouring countries plagued by war and instability, such as Zaire and Mozambique, bring leprosy with them across the borders (Mail & Guardian, 9 June 1997).

Until 1997, patients were mainly treated at Westfort Hospital leprosy clinic outside Pretoria. In accordance to an international trend to treat most patients as outpatients at a local hospital or clinic (AAP, 2000), the 125 year old hospital was closed as part of the government's plan to decentralise the healthcare system. According to the health department, the hospital had been outdated, both physically and in its way of treating people. The "ostrich mentality of a bygone era when lepers were locked away from the rest of society is no longer tenable," was the response of the Gauteng Department of Health (Mail & Guardian, 9 June 1997).

According to Mr T. de Villiers (personal communication, 3 June 2006), vice-director of the Leprosy Mission in South Africa, leprosy patients are primarily the responsibility of the government. In practice there are, however, pitfalls as the primary health care system is not geared to provide specialised care for leprosy patients. The Leprosy Mission therefore still plays a vital role to serve as mediator between the patient and primary health care.

PROGNOSIS OF LEPROSY

Desikan (1997) suggests that emboldened earlier leprologists were hesitant to use the word “cure” in leprosy. Not being sure of a total elimination of the causitive agent, such words as “quiescent” or “arrested” were applied to describe the state of recovery of the disease. Presently, with the introduction of the effective MDT method, it is rather tempting to declare a case as cured. Even so, it is debatable whether in highly-bacillated cases, total elimination is possible. It is reckoned that there could be 10¹² or 10¹³ bacilli in a lepromatous case of leprosy. Even if 99.999% of the germs were killed by medication, the remaining 0.001% of the bacilli would still indicate a significant number. Furthermore, another predicament is the presence of “persister” bacilli, which lie dormant in body tissue into which drugs do not penetrate. The presence of drug-resistant or persistent bacilli could cause a relapse, but it appears as if the small numbers of bacilli remaining viable after intensive chemotherapy are probably taken care of by the body’s general immune system, preventing relapse of the disease.

Despite the possibility of relapse of the disease, Behrman (2000) indicates that the prognosis for terminating progression of nerve damage is good, but recovery of lost sensory and motor function is variable and generally incomplete. Goldman (2000) supports the viewpoint of the above-mentioned author by pointing out that loss of sensory and motor functions are accompanied by irreversible nerve damage. Mandell (2000) stipulates that patients who are fortunate enough to receive an early diagnosis and institution of effective chemotherapy can possibly avoid leprosy’s peripheral neuropathy and consequent deformity and disability. Normally, irreversible deformity and disability occur in the later phases of leprosy and are relatively uncommon today, due to early treatment by MDT. The exceptional conditions in leprosy requiring surgical correction are either the direct result of the disease or secondary to nerve paralysis.

PREVENTION OF LEPROSY

Besides proclamations that are made of controlling leprosy as a public health problem in the near future, disease eradication is even assumed as a possible result of the worldwide implementation of MDT (Mandell, 2000). In order to prevent transmission of leprosy, the focus worldwide has mainly been on early case-finding and to ensure that all existing and new cases are treated properly with MDT by general health services. Furthermore, patients have been encouraged to undergo treatment regularly and completely, and leprosy awareness is promoted in the community to ensure that people with suspicious lesions report voluntarily for diagnosis and treatment. Surveillance and monitoring of progress by the WHO and concerned parties toward elimination of leprosy are also improved (Rakel, 2001).

However, as mentioned earlier, the global incidence of new cases has yet to decline and most current leprosy sufferers reside in areas with inadequate medical infrastructures for the prevention and treatment of leprosy. In most of the leprosy endemic countries high cost of medication, shortage of health workers to identify new leprosy cases and supervision of monthly administered medication, have encouraged several interventions to ensure cost effective and efficient treatment (Mandell, 2000; McDougall, 1997). A possible intervention to ensure efficient treatment and no further physical damage is to supply patients with more than a month's supply of MDT.

Obviously, it seems crucial that patients should be motivated to ensure that daily and monthly components of MDT are taken. Patients who self report for diagnosis and treatment may in some cases be considered as adequately motivated to take full responsibility for their own care, provided they are given proper information with regard to the self treatment of the disease (McDougall, 1997). Furthermore, in some instances the identification of a family or community member who can supervise the monthly drug administration is essential (McDougall, 1997; Rakel, 2001). The experience from many endemic countries prove that, after adequate training, health care workers are able to diagnose and treat leprosy in the field, as well as give

leprosy sufferers and their family members appropriate information and guidance for self treatment based on the clinical signs and symptoms of the disease (Rakel, 2001). Apparently, programme performance has generally improved a great deal in many parts of the world (Desikan, 1997). Drugs are available free of charge and in many leprosy-endemic countries general health services providing leprosy treatment have improved remarkably in recent years.

Progress has been made to such an extent that immunisation is even provided in some endemic areas by general health services (McDougall, 1997). Although there is no effective primary prevention against leprosy, Bacille Calmette-Guerin immunisation (BCG), is known to have some protective effect against the disease in certain populations (Rakel, 2001). According to the AAP (2000) and Cotran (1999) this vaccination is reported to be about 50% protective against leprosy, and one or two repeated doses might even increase the protection further.

According to Van Beers (1999), leprosy control programmes face the problem of many leprosy patients remaining undetected. As previously mentioned, household contact has been identified as a high-risk factor for the transmission of the disease. Behrman (2000) states that the minimisation of the risk of infection among household contacts is advocated for the termination of leprosy transmission in endemic areas. This intervention is based on regular periodic examination of family members having household contact with a leprosy patient and early treatment at the first evidence of leprosy in these family members. Previously, leprosy sufferers had been abandoned from their households as a precautionary measure to eliminate the transmission of the disease. In many cases, being outcasts in the community, they were forced into leprosariums (Behrman, 2000). According to this author, such negative historical practice has fortunately been discontinued. Studies have shown that viability of *M. leprae* in skin biopsies decline sharply within three weeks of initiating therapy with dapsone and rifampin. This dramatic drop in infectivity combined with the high possibility that family members have had prolonged exposure to the patient before the diagnosis, makes physical isolation of leprosy patients unnecessary (Behrman, 2000).

Although leprosy control focuses on early diagnosis through screening of household contacts, this group constitutes only a small proportion of all incident cases. Taken into consideration that “contact” with a leprosy patient is the major determinant in the infliction of this disease, the type of contact is apparently not limited to household relationships, but also includes neighbour and social relationships (Van Beers, 1999). Therefore, leprosy control programmes and elimination campaigns focus on case detection and health promotion in household contact, as well as neighbour contact of leprosy patients (Ji, 1998).

For the remaining incident cases, leprosy control programmes have to depend on self-reporting of patients. Taken into consideration that clinical response is slow and freedom from relapse requires seven to ten years to evaluate, leprosy patients will experience difficulty in self-diagnosis of continuation of this disease (Mandell, 2000). In addition, initial relapse in lepromatous cases is primarily by bacterial increase and seems difficult for the sufferers to recognise skin changes. By the time sufferers identify skin changes and relapse, the bacterial load will have increased considerably with accompanying problems (Desikan, 1997).

REHABILITATION OF LEPROSY PATIENTS

Areas on which leprosy rehabilitation should focus include surgery, physiotherapy and occupational therapy. In areas where treatment has only started recently, there is an accumulation of leprosy patients with physical deformities (Sane, 1999). These conditions of physical deformities, though uncommon, are still found even in areas where leprosy has a low prevalence.

Much of the chronic impairment results from repeated trauma to anaesthetic digits and limbs. The surgical correction of these deformities is essential for the patients' psychobiological functioning (AAP, 2000). Nasal reconstruction surgery, for example, can largely restore the cosmetic defect, making the appearance of affected sufferers socially acceptable (Mandell, 2000). Careful counselling of patients and

consultation with physical and occupational therapy services are essential for optimal rehabilitation of leprosy patients (Behrman, 2000). Patients should therefore have access to facilities where rehabilitation can be performed (Sane, 1999). At these rehabilitation facilities, patients should obtain essential information from occupational therapists on, for example, footwear to prevent continuous ulceration (Mandell, 2000).

In July 1997 Westfort Hospital in Pretoria, that was primarily responsible for the biopsychosocial care of leprosy patients, was closed down. Leprosy sufferers attending this hospital had to make use of the service of local clinics to receive medication. The few institutionalised patients were mainly old aged and were placed in retirement villages. Prior to the closing down of Westfort Hospital, personnel were primarily responsible for the social and occupational rehabilitation of leprosy patients. Although this function is at present mainly the task of the primary health care system, the Leprosy Mission at times still serves as mediator between leprosy sufferers and the primary health care system (T. de Villiers, personal communication, 3 June 2006).

CONCLUDING REMARKS

From the literature survey presented in chapter two, it is clear that the physical difficulties which leprosy patients have to deal with are comprehensive and complex in nature. Against the background of the medical aspects discussed here, it is understandable that the psychosocial stressors which leprosy patients experience are vast. These stressors are highlighted in chapter three.

CHAPTER THREE

THE PSYCHOSOCIAL STRESSORS OF LEPROSY

PATIENTS: THE TURMOIL OF SOCIETY'S PARIAHS

INTRODUCTION

A diagnosis of leprosy exposes patients to a variety of stressors. In order to scrutinise the sense of coherence of participants, it is vital to have a proper understanding of the range of stressors that leprosy sufferers have to bear with.

The discussion starts with a focus on the age-related psychological turmoil that a diagnosis of leprosy evokes. This instability is underlined by a discussion on the incidence of psychiatric disorders in, and suicide of leprosy sufferers. Gender differences in coping with leprosy follow thereafter. Stressors related to the leprosy sufferers' marriage and family life are then attended to. It is followed by a description of stress induced by the broad community and the influence of segregation and institutionalisation of leprosy patients. Stigma can be emphasised as the single phenomena that impacts most negatively on the psychosocial functioning of leprosy sufferers. An in-depth discussion about stigma is therefore included. The dynamics behind non-compliance of drugs and the delay in treatment of leprosy are also covered. A discussion on physical disabilities and facial deformities and subsequent negative consequences on the leprosy sufferers' psychosocial functioning, as well as his or her functioning within the workplace, is also included. The role of medical professionals, rehabilitation and public programmes are also emphasised in this chapter. Religion and a sense of coherence might impact positively on the way in which a leprosy sufferer deals with the disease. This chapter is concluded by a description thereof. References to the psychosocial impact of different culture-specific social systems, and more specific, the South African social system, are interwoven in the text.

THE PSYCHOLOGICAL TURMOIL ASSOCIATED WITH LEPROSY

Leprosy has afflicted humanity for a long time. Emotional turmoil associated with leprosy has been recognised from biblical times (Adachi, 1996). Since ancient times leprosy has been regarded by many communities as being contagious, mutilating and incurable (Wang 1997). It once affected every continent and it has left behind a terrifying image in history and human memory of mutilation, rejection and exclusion from society. Indeed, in some cases the mere diagnosis of leprosy is sufficient handicap for the affected person, even when there is no disability. To date, people with leprosy are still regarded as society's pariahs. The general public views them as having poor health and quality of life. Literature on the experiences of leprosy sufferers emphasises the dimensions of hopelessness, helplessness, suffering, restriction, disabilities and deformities.

The abovementioned emotional reactions to leprosy are confirmed in a South African study by Scott (2000) on the psychosocial needs of leprosy patients. In his interviews with 30 leprosy participants, the researcher asked the participants to explain the nature and intensity of a variety of emotions that followed directly after the diagnosis of the illness. They had to grade the intensity of emotions, for example anger, grief or fear. Heartache, fear and bewilderment were the most common emotions experienced directly after the diagnosis. Acceptance of the disease and hope for the future scored very low. Participants blamed God, their ancestors, relations and family members for the disease. Many of the participants did not know who infected them. This could possibly explain why only 10 participants felt aggression towards the person that had given them the disease. Intense grief was the most common reaction on hearing the diagnosis of leprosy.

Leprosy is a disease that destroys not only the body, but also the soul. According to Bainsan and Van den Borne (1998) and Antony and Broota (1991), the emotional turmoil that the leprosy sufferer experiences is intensified by the adverse reactions of the community. As the patients are prohibited from participating in the social and economic activities of the community, they become fearful, withdrawn, isolated and lose self-confidence and self-respect. It is difficult to imagine a socially created status more damaging to self-esteem than that of leprosy (Brand, 1995; Covey,

2001). Eventually, the leprosy sufferer loses social status and becomes isolated from society, family and friends. Frustrations with employment, crippling deformities and social ostracism may finally force him or her into alcoholism, begging and adoption of a hostile attitude towards society. This condition is known as Dehabilitation. Eventually, a leprosy patient may be forced to leave his or her home and settle in a rehabilitation home or leprosy colony with other leprosy patients. This final stage is known as destitution (Bainson & Van den Borne, 1998).

A diagnosis of leprosy might have an adverse impact at different developmental stages. Scott (2000) reports cases where even children became abandoned and isolated. In a study by Chauhan and Dhar (1980), the authors maintain that if an adult is inflicted with this disease, he or she will develop a defense mechanism(s) suitable to the situation; for example, he or she will rationalise some of the agonies. However, a child suffering from leprosy in the formative years does not have well developed defence mechanisms. The lack of fulfilment of basic needs such as acceptance, achievement, affection and security might acutely jeopardise the child's psychosocial development. Furthermore, children suffering from leprosy perceive their immediate environment as hostile and insecure rather than friendly and show marked sibling rivalry because of non-fulfilment of a need of love and affection. Segregation and the fact that they are deprived of the usual privileges of home environments lead to anxiety and they cope with their illness and hospitalisation by using the defence mechanisms of identification, regression, isolation and withdrawal. They seem to have weak egos and lack independence in feeling, thinking and action. As a result of defeat and unsuccessful coping with new situations, they often withdraw and try to live in fantasies of the past. On the whole, these patients lack ego integration and poor adjustment abilities (Chauhan & Dhar, 1980).

The incidence of psychiatric disorders in leprosy patients

Scientific inquiry into the psychiatric aspects of leprosy started in the nineteen-sixties. At that time, the stigma attached to leprosy was significant; and isolation by way of institutionalisation was an important mode of treatment. Studies conducted were mainly on institutionalised populations with no controls. These studies were

usually descriptive, and focused more on psychological effects of being institutionalised than on the psychiatric morbidity secondary to the physical ailment (Bharath, Raghuram, Shamasundar & Subbakrishna, 2001). Modern research conducted after the initiation of effective chemotherapy and community care, has confirmed the increased prevalence of psychiatric morbidity in those afflicted by leprosy in comparison to the normal population.

In the recent past, a few comparative studies were done with other chronic dermatological conditions like vitiligo and neurodermatitis. Apart from anxiety and depression, an excess of suicidal ideas and paranoid symptoms were recognised in participants in these studies, and were related to psychological issues like body-image disturbance. In a study by Bharath *et al.* (2001) the severity and pattern of psychopathology in leprosy patients in comparison to another chronic disfiguring dermatological condition, namely psoriasis, was researched. Results in this study indicate that the psychiatric morbidity among the leprosy-affected persons was significantly more severe than in those with psoriasis. Certain issues related to psychiatric morbidity in patients with leprosy have been identified by this study. Research by Thomas (1983 unpublished report) showed contrasting results (Bharath *et al.*, 2001). It is evident that research in this area is inadequate to come to firm conclusions on whether psychiatric morbidity in leprosy is more or different from that associated with other chronic dermatological diseases.

In a study by Chatterjee, Nandi, Banerjee, Sen, Mukherjee and Banerjee (1989) in a hospital in Purulia (India), it was found on a global clinical assessment, that 64.7% of these in-patients were mentally morbid. All the cases were suffering from depression. Olivier (1987) stated that 10% of patients at the Carville Leprosarium in Louisiana (USA) were psychotic in 1953. Despite several reports on psychiatric problems in leprosy, the prevalence of psychosis is still controversial. Several authors deny any association between recognised forms of psychosis and leprosy (Adachi, 1996).

Suicide by leprosy patients

The moral-ethical dilemma whether a human being suffering from an incurable and distressing disease should be permitted to terminate his or her life, and whether sympathisers should facilitate the act, still confronts society (Pandya, 2001). The morality of suicide was debated by many of the writers on Hindu civil law and ethical codes. Taking one's life was generally considered such a reprehensible act that purification rights were denied to those who committed suicide. However, the injunction could be, and was, waived in exceptional circumstances (Pandya, 2001). The sage Atri, for example, was of the view that

if... one who is ill that no medical help can be given, kills himself by throwing himself from a precipice or into fire or water...mourning should be observed for him for three days (Pandya, 2001, p. 29).

In Manu Smṛti, according to the commentator Medhatithi (circa 900 AD), suicide by the above methods was justifiable for a person suffering from advanced leprosy. For relatives to assist such a suicide was regarded as a benevolent and dutiful act. By resorting to *samadh*, as this practice was known, the sufferer could expect the privilege of customary funeral rites and rituals, as well as release from similar diseases in future births (Pandya, 2001).

While it is not possible to say how frequent the practice was, Henry Thomas Colebrook (1765-1873), the jurist and renowned British Orientalist, told of an attempt to bury alive a young man afflicted with leprosy. Colebrooke remarked that leprosy is the disease that most frequently impels the wretched sufferer to seek relief of his or her misery in a grave. In the princely states of Katiawar in the Gujarat peninsula, the leprosy sufferer's chosen end was likely to be a solitary affair - jumping off a cliff into the sea at a holy site such as Gopnath (Pandya, 2001). The degradation and humiliation associated with the intense stigma of leprosy in a tradition-bound country like India is likely to affect the mental health of the victim to such an extent that over 33% of participants in a study in a Leprosy Mission Hospital in Purulia (India) considered committing suicide (Chatterjee *et al.*, 1989).

Suicide is not to be construed as a unique phenomenon of Indian Society. Gussow and Tracy (1968) have discussed the phenomenon of social stigma associated with leprosy in parts of the United States. The sense of despair and apprehension for a disease that is castigated by the society and dreaded by the victim as almost incurable may predictably act as a serious psychological stressor. In a South African study by Scott (2000), eleven (of thirty) participants contemplated suicide.

GENDER DIFFERENCES IN COPING WITH LEPROSY

The lower social status of females typical of many cultures may result in greater suffering among women who suffer from leprosy. It is also likely that the lower social status in itself, may contribute to gender differences in the detection and treatment of this disease. A couple of factors might influence the course of the disease, amongst others, a lack of knowledge about leprosy, its causation and treatment (Rao, Garole, Karandikar, Khot & Walawalkar, 1996).

Knowledge and treatment seeking

One of the major factors that adversely affect the control programme is the delay in treatment. Even after identifying the initial symptoms of the disease, there is likely to be a further delay in receiving the formal treatment owing to differences in the health-seeking behaviours of male and female patients (Le Grand, 1997; Rao *et al.*, 1996). For example, literacy and awareness levels have a key impact upon the utilisation of health services. Specifically, if women have a poor understanding of causation, symptoms and available health care, then services (however efficient) will not reach the target population (Morrison, 2000).

The results of a study by Le Grand (1997), suggest that women were generally less aware than men of the symptoms of leprosy and the availability of leprosy services. Worldwide, case-detection rates of leprosy vary considerably for men and women. In most areas of the world case-detection rates are higher among men than women, at least in its clinical forms, at a ratio of 2:1. In India, leprosy was traditionally

thought to result from the “wrath of God”. This resulted in women delaying treatment until measures such as fasting and offerings had been made (Morrison, 2000). One of the major reasons for the delay in treatment was observed to be the exclusive dependence of female patients on non-formal treatments, for example religious approaches or the treatment given by traditional healers, in the initial stage of the disease. In a study among Pakistani patients it was observed that many patients had lost years of effective treatment as a result of opting for non-formal treatments. African women are more likely to try over-the-counter remedies first, followed by traditional healers, and then health clinics (Morrison, 2000).

It was also the observation in a study by Rao *et al.* (1996) that relatively more women compared to men tend to hide the disease. A substantial and slightly larger number of female patients suffer from anxiety due to a lack of sufficient information about leprosy. Female leprosy patients were, for example, reported to be reluctant to get registered as patients for fear of bad treatment from the family, especially from their husbands. For this reason, they were more irregular in attending clinics and drug delivery points compared to male patients. Due to fear of identification as leprosy patients, female sufferers would be reluctant to use micro cellular rubber footwear that is vital for the preservation of their feet (Rao *et al.*, 1999). The observed gender differences in case-detection rates could also be due to women having less access to and making less use of health services. Several studies on gender differences in utilisation of health services show that women have less access to sufficient health services than men (Le Grand, 1997). The quality of health services available can provide major barriers for leprosy patients having to see a male doctor. In Western society women can choose to see female doctors if they wish, but in developing countries this service is not always available.

The association of low case detection with a specific age group could be related to religious and cultural taboos, for example, girls and women who are not yet married are not allowed to show their body to male health staff and hence are not visiting health services and/or are not properly examined and diagnosed (Morrison, 2000). By not catering for both sexes, health care services reflect a poor understanding of

the needs of female patients. In India and parts of Africa, this lack of gender awareness is particularly problematic (Morrison, 2000).

Lack of time, money and mobility are more often causes for poor treatment compliance among female patients (Le Grand, 1997; Rao *et al.*, 1996). Furthermore, they are unwilling to disrupt household duties or are not able to find caretakers for their children. Women tend to be the main health providers for their families, and as such suffer the greatest impact from diseases. They often have to carry the additional burden of caring for other members when ill (Le Grand, 1997). To spend their time and money seeking personal health care may involve confrontations with husbands or mothers-in-law, and guilt from leaving the family uncared for. In many countries women's access to health care is determined by their status within the family. In India, the decision to call a doctor is generally taken by men or the mother-in-law. A married woman often delays seeking treatment because of the husband's apathy or because of jealousy of the mother-in-law. Similar lack of decision-making power for women is found in many other countries in Asia, Africa and Latin America (Morrison, 2000).

However, evidence indicates that women are more compliant with drug treatment than men. African women also combine modern treatment with traditional medicine. This is satisfactory because most traditional healers do not believe that modern and traditional African medicine should be mutually exclusive. The stigma associated with leprosy ultimately acts as a barrier to seek proper medical care. Women's fears center on damaging their marriage prospects, losing their husbands, children and homes, as well as inflicting the stigma associated with the disease onto their children. In Nepal, fear of stigmatisation was found to be an important reason for some ethnic groups' patients to visit treatment centres far from home. For men, the disease does not lead to such severe consequences. In India, women hide their symptoms for longer than men do for fear of stigmatisation (Morrison, 2000).

Impact on daily life

Some women with leprosy face definite social and psychological problems on a daily basis irrespective of their socio-economic status (Rao *et al.*, 1996). There are reports on women being pressurised to leave the family home, but certain factors influence them to remain, namely motherhood, strong marriages and husbands that are supportive in finding treatment. Where women remain with their families in South India, they are often banned from sleeping in the same room as their spouse and family. Family reaction to a diagnosis of leprosy is not as well documented in Africa. It appears that, in the early stages, individuals remain well integrated in their families. Later, as deformities develop, sexual relations are prohibited and divorce is easily secured. In Brazil, women tend to remain single, separated or widowed, live with relatives or with their children without their spouse, and indicate leprosy as a reason for family separation (Morrison, 2000).

It was observed that by and large women with leprosy were more isolated from all activities than men. In a study by Rao *et al.*, (1996), most women (80%) in the study were isolated from their major daily task of cooking food and caring for children. It was probably the fear of contaminating others that isolated them from their daily activities. Isolation from touching others was again a strong reaction that many women (84%) faced, unlike men (17.7%). This is enforced by spouses, or by women who voluntarily withdraw for fear of contaminating the rest of their family. Loss of freedom to touch and to be touched, especially their children, symbolises rejection and does not reinforce female caring roles (Morrison, 2000). While men and women are both negatively affected by leprosy, the extent of the impact amongst women appears to be mainly in terms of isolation, rejection from spouses, children and relatives, loss of freedom to touch and other restrictions (Augustine, Joseph & Rao, 1999). The power and influence of men within the family structure enable them to maintain their position in the household more frequently than women. Finally, more women than men suffered from isolation in attending the festival celebrations in their own family. Such isolation from vital domestic roles develops, among women, a self-image of being a useless member of the family (Morrison, 2000). In a study by Rao *et al.* (1996), a significantly higher proportion of women patients (81 %) suffered from low self-esteem compared to men (70 %).

Interaction with the community

Family influence is known to act as a powerful force determining a significant portion of observed and reported behaviours of patients. The disease does not only affect day-to-day functioning in the family, but considerable restrictions are enforced on patients due to the fear of social stigma. More women seem to have these restrictions than men. For example, in a study by Morrison (2000), 30% of women in this study reported constraints on social outings with the family and travelling. Attending festive celebrations in the neighbourhood was also prohibited for women (17.9%). Only 10% of men experienced restrictions regarding the attendance of festive celebrations. Thus, although men and women were both affected in terms of their social life, women suffered more isolation and rejection from family and society, clearly reducing the mobility of women patients even more (Morrison, 2000).

Leprosy had a generally adverse effect on both male and female patients. However, while it leads to introversion and depression among female patients, it is mainly the male patients that fit into the stereotype of the aggressive personality of the typical leprosy patient. As most female patients are housewives, leprosy does not have much impact as far as occupation and income are concerned, as opposed to males who generally have problems with securing or holding on to lucrative jobs, with consequent loss of income (Morrison, 2000).

IMPACT OF LEPROSY ON MARRIAGE LIFE

A diagnosis of leprosy, impacts negatively on the marital prospects of patients and, generally implies a lower quality of life (Bainson & Van den Borne, 1998; Kopparty, 1995). Furthermore, the disease may exert tremendous pressure on the relationships of leprosy sufferers who are married. It is substantiated by the fact that the divorce rate among the leprosy-affected is relatively high, even in the Indian cultural context that does not generally favour divorce (Awofeso, 1995; Raju & Reddy, 1995). For example, The India Christian Marriage act (1872), the Muslim Marriage act (1939), and the Hindu Marriage act (1956) granted divorce on grounds

of leprosy (Krishnatray & Melkote, 1998). While in some parts of the world, long periods of hospitalisation have been identified as the single most important cause of divorce, in Nigeria, it is the presence of stigmatising deformities that usually rocks such marriages (Awofeso, 1995). Although Awofeso (1995) maintains that a man is more likely to divorce his wife should she contract leprosy than vice-versa, in a survey of a Zambian leprosy colony, more males than females reported that their spouses had left them after diagnosis (Morrison, 2000). A similar trend was established in a South-African study by Scott (2000) where nine men opposed to seven women (in a group of twenty-three) were deserted by their marriage partners because of leprosy. Contributory factors leading to this were an inability to provide security (psychological, social and economic), as well as problems concerning sex with the spouse. Of the 21 leprosy sufferers who were partners in a sexually active relationship, nine were less active after they had contracted the disease. The following reasons were suggested for this decline:

- A decline in physical strength.
- Impotence.
- Uncertainty about the true feelings of the sexual partner. Some leprosy sufferers were hesitant to make a sexual approach, being under the impression that their spouses had a fear of contracting the disease and therefore did not wish to have sexual intercourse with their partners.
- Embarrassment by ulcers.
- Afraid of possible transmission of the disease.
- Marriage partner was fearful of contracting the disease.

IMPACT OF LEPROSY ON FAMILY LIFE

Family influence and pressures are known to act as a powerful force determining a significant portion of observed and reported behaviours of patients. Supervision and encouragement of family members may for example play a significant role in leprosy control. For example, drug compliance could be significantly increased if family members (who have proper knowledge of MDT) took a keen interest in helping a patient by giving more supervision and encouragement regarding the intake of

medication (Bian, Chen, Chen, Jiang, Li, Wang, Ye, 1997). Furthermore, leprosy does not only affect the day-to-day functioning of the family in a negative way, but considerable obstructive restrictions are enforced by families on patients due to the fear of social stigma (Ogden & Porter, 1999; Raju & Reddy, 1995; Rao *et al.*, 1996). In most disabling conditions, neither the family nor the public set out deliberately to make life difficult or unpleasant for the patient. It is just that people perhaps do not think about what it means, for example, to a wheelchair-bound person to be faced with several steps on the way into a home or office (Brand, 1995). In the case of leprosy, however, there is often some kind of deliberate purpose behind the attitudes of the family and the community. People fear the disease and it is thought to be highly infectious, incurable and the patient is therefore excluded from society. However, the stigma of leprosy is not from the germs, which only the doctors can see, but from the deformities and the ulcers that are visible to everybody. These are not corrected by the medicine that kills the germs and allows the patient to be listed as “cured”. For example, people see a patient rubbing an inflamed eye while the lids are not closed and this is regarded as a sign of active leprosy and the patient is consequently shunned and turned away from his or her home (Brand, 1995). Rejection may, however, depend on the nature of handicap. This shows that as long as the deformity does not turn out to become a handicap, the deformed patients are accepted more widely than the handicapped (Kopparty, 1995).

Another factor that may play a role in stigmatisation of the leprosy sufferer by his or her family is that leprosy (like tuberculosis) is perceived as a hereditary ‘family disease’ because it is recognised as related to a specific family (Caprara, 1998). The social stigma of having a family disease, along with medical costs, can sometimes be too much for a family to bear. It is therefore not uncommon for patients to be abandoned by their own families, especially if they are very poor and there are other children to be cared for (O’Brien, 2000; Tare, 1991).

In a South African study conducted by Scott (2000), rejection by (extended) family members appeared quite frequently, as 10 (of 30) participants’ families had rejected the leprosy sufferer after diagnosis. Many of the participants kept the name of their

disease secret. When participants did make it known, 20 were rejected by their friends. Fear of the transference of the disease is accepted as the largest single cause for rejection by family members. Navon (1996) maintains that, in some cases, abandonment within the leprosy sufferer's home occurs. For example, many of the leprosy sufferers in Thailand whose disease was diagnosed before the 1950s, continued residing at home with their families. However, they were confined to a separate room, their relatives and friends avoided eating from their dishes or touching them. Below is a typical account of the conditions in which such leprosy sufferers used to live:

The disease was diagnosed when I was 13, and I was kept in a room at home until the age of 27. Everything was kept separate: I ate from different plates, and even washed my clothes by myself, in my room. My family treated me well. They would encourage me and come into my room to talk, but they wouldn't allow me to dine with them or to sit in their rooms. At first, several friends wanted to visit, but I was ashamed of my appearance, and later on they left me alone. I spent most of my time reading, and hardly ever left the room. At first it was very difficult, and I even tried to commit suicide. But after living like this for a long time, one gets accustomed, because there is really no choice (Navon, 1996, p. 462).

Testimonies of childhood suffering of people contracting the disease as a child, such as the above, are not uncommon. The agony is far more encompassing, as it is not only the patient, but also the family members who are subjected to the tremendous problems they have to face. Children of leprosy sufferers, for example, directly or indirectly, become targets of the unfavourable attitudes of the society. They have problems regarding schooling, getting jobs and getting married. Only because their parents have leprosy, they are thought of as carriers of the disease and thus, considered as outcasts and untouchables by the society (Antony & Broota, 1991). Children of leprosy patients are found to have poorer self-concepts, compared to

children of parents who are not diagnosed with leprosy. The needs of a child are highly dependent upon and influenced by how the child perceives his or her parents. The child of leprosy patients interacts with the parents who have a negative self-image, feelings of inferiority, helplessness, depression, shame and guilt that are associated with not only the bodily disfigurement but also the various misconceptions like the belief that leprosy is the punishment for past sins and immoral behaviour (Antony & Broota, 1991).

STRESS INDUCED BY THE COMMUNITY

Segregation and institutionalisation are in some cases a direct outflow of the rejection that leprosy sufferers experience from the broad community. To be segregated and institutionalised, is a huge stressor that leprosy patients have to deal with. A discussion on this phenomenon follows.

Stress related to segregation and institutionalisation

Some medieval communities treated individuals suffering from leprosy similarly to ordinary citizens and with compassion (Covey, 2001). There is, however, consensus amongst authors that leprosy sufferers caused horror for contemporaries; they were discarded from society when identified without a chance to return (Anandaraj, 1995; Anderson, 1998; Tare, 1991). It was forbidden for them to touch babies, enter churches, markets and other assemblies of people and to wash in a stream of water of any kind. Furthermore, they had to drink only from their cup, go only in leper's dress, they were forbidden to touch anything and anybody with naked hands and had to eat and drink only in the company of leprosy sufferers. People ran away from them through fear of the loathsome disease and consequently, either at the bidding of their families or (more often) at their own initiative, leprosy sufferers moved to a solidarity hut on the outskirts of the village or in the nearby jungle (Navon, 1996). Separation would have also provided communities with a way to limit begging and contributed to a sense of membership and belonging amongst those with the disease (Covey, 2001).

Missionaries who came across such people with leprosy described their living conditions in terms of ostracism and expulsion, yet indicate that in most cases family members, and occasionally friends, frequently visited these leprosy sufferers and brought them food. Certain priests attended to the leprosy sufferers, and allowed them to live on the premises of the temples. When several people with leprosy were kept in solitary huts, a “leper village” developed alongside the original place of residence, but its dwellers were still regarded as members of their community and their next of kin provided them with financial and emotional support. Leprosy sufferers without relatives to support them could also find shelter in Buddhist temples, where special accommodations were set aside for them and both monks and worshippers brought them food (Navon, 1996).

Often treatments in these settings were a combination of physical treatment and spiritual interventions. These were based on the belief that the treatment should include both spiritual and physiological aspects. To address the spiritual aspects of the disease, the church established and maintained leprosariums. Some medieval physicians openly admitted to the difficulty of curing the disease except through divine intervention. With the apparent lack of successful medical treatment, public efforts focused on isolating and caring for people with the disease. Leper houses were common during the Middle Ages. Typically, these hospitals had walls, private gardens, chapels, cemeteries, and were located outside town limits. Despite the isolation, hospitals were often open to family members (Covey, 2001). Family support, however, is not sufficient comfort for patients in dealing with their concerns whilst hospitalised. In a South African study by Scott (2000), all participants (30) worried while they were in hospital. Factors that caused the most worry were: financial matters (23), spouse and/or children while still married (30), subject’s attendance at work (28) and the possibility that the subject might lose his or her job. The majority of leprosy sufferers in this study felt that lengthy institutionalisation and hospitalisation had more disadvantages.

However, the enforced isolation of leprosy patients into institutional settings has been a common method worldwide for containing the disease. Mandatory isolation by the thousands was the only known way of protecting the healthy community from a feared infection (Bloombaum & Gugelyk, 1979). A review of the medical literature by Anderson (1998) points to consensus among medical experts decades ago that only isolation and segregation could accomplish the eradication of the disease. This policy imposed many hardships upon the leprosy sufferers themselves and their immediate relatives and friends, but it was believed to be fully justified in order to save hundreds from contracting leprosy and also to provide victims as pleasant a life as possible. The life of leprosy patients in these institutions seemed inactive, because they were isolated, received financial support from the government and had physical dysfunctions (Goto, Hagio, Kimura, Kitajima, Sato, Tokunaga & Ueda, 1995).

From the 1950's onwards, medical care of leprosy all over the world profited from the discovery of effective drugs and from the introduction of reconstructive surgery and modern physiotherapeutic methods (Navon, 1998). In the last fifty years, the institutional system of segregated leprosaria, leprosy dispensaries, special orphanages, settlements, and associations has been gradually disappearing as people realised that segregation was not justifiable for medical, financial, or ethical reasons (Frist, 2000). The treatment of the disease was gradually integrated into the general health services, and laws discriminating against its sufferers were repealed. Many patients who had lived for years in special hospitals for leprosy sufferers were discharged, and most newly diagnosed were detected before the appearance of visible symptoms and treated ambulatory. The majority of patients living within the general community who were diagnosed from the 1970's onwards lead entirely normal lives and enjoyed full social acceptance (Navon, 1998). More leprosy sufferers are gaining the self-confidence to openly reveal their diagnosis and to speak out (Frist, 2000).

On the contrary, Staples (2004) conducted interviews with leprosy sufferers in Andhra Pradesh (South India) and their overwhelming response was that they preferred the

benefits of living in colonies to the isolation and poverty that they had experienced as leprosy victims back in their original communities. This was the case even for the large proportion of people who had not been explicitly rejected by their families or told to move away. From the outset, this marks a major difference between some patients' perceptions and the theory that leprosy sufferers should be re-integrated into their original communities. At the simplest level, being part of a leprosy colony offers a form of sanctuary from what was seen as a hostile outside world (Staples, 2004). Similarly, Tare (1991) conducted a study in respect of patients discharged from two supposedly ideal rehabilitation centres and reported the sad revelation that the majority of trained-and-discharged patients were not continuing the trade-craft in which the training was provided and had become either beggars or agricultural labourers (Tare, 1991).

However, the ethical justification of institutionalisation and practices to limit the spreading of leprosy is surely a debatable issue. In Japan, the Japanese government was ordered to pay US 29.1 million in compensation on 11 May 2001 for violating the human rights of leprosy patients who were sterilised, forced to have abortions, and isolated in remote island communities. This policy continued up to 1996, long after the development of effective treatments for leprosy patients and studies showing that the disease was rarely contagious. Despite the end of the isolation programme in Japan, there are still 4400 people living in 15 leprosy treatment facilities nationwide. Many patients are elderly people who feel they will shame their families if they return home (Watts, 2001). In South Africa a process of de-institutionalisation was initiated which implied the closing down of Westfort Hospital in 1997 as the main setting where patients were institutionalised.

THE ROLE OF STIGMA ON THE PSYCHOSOCIAL FUNCTIONING OF LEPROSY SUFFERERS

Definition of stigma

“Stigma may be defined as negative attitudes and prejudice towards a person that result in avoidance of social interaction” (Krishnatray & Melkote, 1998, p.328). Stigma is a word that was originally used by the Greeks to refer to bodily signs used to expose something unusual and bad about the moral status of the signifier (Bainson & Van den Borne, 1998). Another view is that any quality or trait that marks its bearer as unacceptable or inferior in a particular culture creates a stigma, or a “spoiled identity” (Bower, 2001). Stigmas commonly result from a transformation of the body, blemish of individual character or membership in a despised group. The meaning of stigma has been extended to embrace any mark or sign of perceived or inferred conditions of deviation from a prototype or norm. Furthermore, stigma might be considered as representing a negative outcome or unwanted effect (Bainson & Van den Borne, 1998). The “undesired differentness” of a person relates to attributes of physical disfigurement, blemishes of individual character or personality or both, and social categorisation such as race, national origin, and religious affiliation (Krishnatray & Melkote, 1998). The stigmatised individual usually feels a sense of shame, guilt, and disgrace. Researchers have focused on self-esteem losses and other personal consequences of being stigmatised. It is, however, obvious that there is no scientific consensus on how to define and measure stigmatisation (Bower, 2001).

The stigmatisation of leprosy sufferers

Leprosy is one of the oldest diseases known to humankind, and for centuries people with the disease have been stigmatised (Chauhan & Dhar, 1980; Morrison, 2000; Obregon, 1996). Perhaps no other human disease, since the periodic outbreaks of plague and the rise of the HIV epidemic, has provoked stronger social responses (Covey, 2001). According to St. Louis (1999), a variety of (negative) social stereotypes have surrounded people with the disease and Krishnatray and Melkote (1998) describe the disease as the ultimate in physical disfigurement and negative social consequences. This situation seems to be related to the fact that leprosy deforms and disables but seldom kills, so that those it has crippled live on getting

steadily worse and yet for all to see (Antony & Broota, 1991). In developed countries, leprosy is little known yet conjures up visions of deformed, fingerless beggars sitting in busy market squares or street corners in the slums of India or Africa. The fact is that a lot of times the negative prejudices and actions that we attribute solely to the leprosy stigma may in reality be based on other stigmas. People affected by leprosy are often poor, out of work, uneducated, deformed, disabled, or of a lower social class. These conditions carry their own stigmas in most cultures. To blame all discrimination of people affected by the disease on the “leprosy stigma” is therefore to oversimplify the real situation (Frist, 2000). It is this stereotypical Western view of leprosy that emphasises the stigma inflicted upon people with leprosy (Morrison, 2000). Yet researchers are currently at odds over the intensity of this stigma, its sources, and the reasons for its persistence, despite the discovery of a cure for the disease and dramatic advances in its treatment (Navon, 1998). Scientific uncertainties and the social rejection of leprosy patients played a significant role in the social and political construction of leprosy (Obregon, 1996). Leprosy is unique in its psychosocial aspects and it is difficult to analyse the traumatic experiences to which not only the patient, but also the family members are subjected (Morrison, 2000).

Six dimensions of stigma

- Jones, Farina and Hastorf (1984), ordered disfigurement-related stigmas affecting social interaction along six dimensions. The first dimension of *concealability* refers to the hidden or obvious condition of stigma. Visible conditions attract high stigma and impede social interaction, whereas low visibility conditions permit the bearer of stigma to interact with greater ease.

In general, among stigmatising conditions leprosy fares poorly on the concealability scale, because most of the deformities occur on the head, the hands or the feet. Consequently, they are very visible. A patient with severe deformities of the hands, feet or head continually bears the mark of the disease and, consequently, stands in perpetual danger of being stigmatised. It must,

however, be added that even a patient who bears no external mark of the disease may suffer some stigma if he or she discloses his or her history (Bainson & Van den Borne, 1998). Some medieval communities expected people with leprosy to wear special clothing as warnings. Special clothing allowed others to avoid them and symbolised them as social outcasts (Covey, 2001). Long robes, gloves, horns thrown over the shoulder, were typical gestures of costumes. Leprosy sufferers sometimes sewed yellow crosses or the letter “L” to their capes or red signs in the shape of a goose or duck foot were sometimes worn over the person’s chest. They also tended to wear gloves with grey or white wool robes and masks over their mouths. Communities even had social expectations on how the clothing was worn (Covey, 2001). When some of the leprosy sufferers went out to beg, they would wear rags and expose their deformities by stretching out misshapen hands and baring the feet to display their mutilation. However, living off charity was generally viewed as deterioration to the lowest social standing. Since dogs are perceived in Thai culture as contemptible and worthless animals, their equation with beggars clearly illustrates the latter’s extreme degradation (Covey, 2001).

- The second dimension on which stigma differs is its level of *disruptiveness* (or obtrusiveness). Disruptiveness can be thought of as characteristics that make social interaction uncertain, unpredictable, or awkward for participants. For example, the electoral laws in the USA once disqualified patients from contesting elections, and the various local accommodation acts authorised owners to evict them (Covey, 2001). Some patients would then rather conceal their illness than suffer the social rejection, which may accompany revelation of the diagnosis. In addition, for fear of being stigmatised, some patients may discontinue chemotherapy prematurely. Stigma would therefore have adverse consequences for the leprosy sufferer and leprosy control (Bainson & Van den Borne, 1998).
- The third dimension of *aesthetic quality* refers to how physically unattractive the stigma may be. Physical disfigurements that appear repellent, ugly, or upsetting evoke more stigmas. It was associated with ugliness, hopelessness, and inferior status and its victims were perceived as ‘living dead’ and compared to stray dogs

and ghosts. Evidence on the prevalence of such views and of the disease's association with dogs, ghosts, misery, and social rejection can also be found in reports written before the 1950's. For example, a Siamese official is quoted as proclaiming of leprosy sufferers that 'they are all dead people' (Covey, 2001).

- The fourth dimension is the condition's *origin*. The extent of interaction depends on how responsible a person is held to be for the stigmatising conditions. This dimension refers to how a "mark" came to be, including when the mark originated during the course of life, the rapidity or slowness of its onset and the afflicted individual's role in engendering his or her own mark. In leprosy, this dimension covers areas such as the perceived cause of the disease and the interpretations made of the perceived cause. Bainson and Van den Borne (1998) are of the opinion that the significance of the perceived origin is related to the cultural environment of the leprosy patient as well as the perceived role the individual has in bringing about his or her affliction.
- The fifth dimension is the *course* of stigma over time. Interpersonal contact is less with those whose condition is perceived as irrecoverable (Bainson & Van den Borne, 1998). The course of a mark focuses on the pattern of change over time and its ultimate outcome. Gussow and Tracy (1968) described eight criteria that ultimately influence social rejection. Three of these are related to the course of a disease. These are, that the condition should be progressively crippling and deforming, that it should be non-fatal and chronic, and that it should appear to be incurable. Leprosy meets all three criteria (Bainson & Van Den Borne, 1998). Leprosy sufferers had to bare the brunt on the basis of their perceived disabilities. For example, The Motor Vehicles act (1939) prohibited them from obtaining a driver's license, although only 25% suffer from sensory loss of the limbs. Provisions in the legal manuals of public transport companies imposed travel restrictions (Covey, 2001).
- The sixth and final dimension on which to locate any stigma is *perceived peril*, that is, the extent to which others feel physically, psychologically, or morally

threatened by the stigmatising condition. According to Sabin (1993), behavioural involvement is avoided with those whose condition is perceived as risky for physical or social well-being. Threat may be perceived when the disease is believed to be contagious, or where leprosy patients are considered to be ritually unclean, or where, as in certain cultures leprosy patients are believed to be witches. For example, Anderson (1998) reports that money handled by some leprosy sufferers never reached the outside world; the authorities coined a special currency to serve as the medium of trade. In effect, this was an insular schooling in abstracted small-town American pieties (Anderson, 1998). Medieval communities implemented other precautionary measures, for example, where people believed leprosy could be spread through breath, people with the disease were only permitted to communicate when they were downwind. Rules also often required that footwear be worn to avoid the spread of leprosy. The pervasive view relies upon historical and contemporary evidence that indicates that across cultures leprosy sufferers have been feared, shunned, ostracised, and subsequently obliged to live by begging. Their despondency sometimes led to begging, drunkenness and troublesome behaviour. Historically, people with leprosy have been forced to attend their own funeral mass and sent into permanent exile (Covey, 2001). In certain cases they were persecuted to the extent of being stoned, poisoned, shot, flogged to death, buried alive or burnt at the stake. There are reports of cases where people spat in their faces and where there was wilful damage to their crops and fields (Navon, 1998). Roaming the roads and markets, wandering in the villages from door to door, they attracted constant public attention to the disease and constructed its image as the most rejected of all medical conditions (Covey, 2001). The sight of the severely disfigured patients evoked fears that they might contaminate people, places, and objects that they come into contact with. However, the stigmatisation of leprosy sufferers endures, and even authors who see eye to eye on the severe stigmatisation of leprosy, do not agree about the sources of this attitude and the reason for its persistence over the years (Navon, 1998). In a recent South African study by Scott (2000) the intense grief that the leprosy sufferers experienced could partially be attributed to their belief that leprosy is incurable.

Furthermore, they felt rejected by fears of relatives and the community regarding the contagiousness of the disease. Twenty-six (of 30) patients reported that people were afraid of physical contact with them. Two of the possibilities for the continuation of the stigma are the role of religion and medical aspects of leprosy, which will be discussed briefly.

The role of religion in the stigmatisation of leprosy sufferers

Christians considered leprosy (well into the twentieth century) to be a moral disease. This belief was based on The Old Testament that portrays a skin disease suggestive of leprosy as divine punishment for immorality and cause for a person's removal from society (Bower, 2001; Covey, 2001; Rao *et al.*, 1996). Many of the (current) social responses to people with the disease are based on biblical teachings (Antony & Broota, 1991). The Bible alone makes about 50 references to the disease (Covey, 2001). For example, Leviticus 13:44-46 states,

Now whosoever shall be defiled with leprosy, and is separated by the judgement of the priest, shall have his clothes hanging loose, his head bare, his mouth covered with a cloth, and he shall cry out that he is defiled and unclean. All the time that he is infected and unclean, he shall dwell alone without the camp.

The moral connotations of the disease have been expressed throughout history. For instance, Pope Gregory the Great (540-604) viewed people with leprosy as heretics. In a similar vein, people have perceived those with leprosy as moral perverts who have heightened sexual desires. By virtue of being considered an evil outcast, people with the disease were symbolic representations of evil. Leprosy was a warning to all living that their sinful lives might result in God's punishment. Viewed as dysfunctional and disruptive because of the fear of contagion and the assumed immortal nature of the disease, the leprosy sufferer was functional in reaffirming the moral order (Covey, 2001). Another possible reason for its continuation is that leprosy organisations that raise funds for leprosy work often depend on a negative

image of leprosy. The disease has been portrayed as a disease of special religious significance, and stories have been told of the extremely deformed and ostracised, to trigger donor generosity for the support of their programmes (Frist, 2000). Furthermore, the massive involvement of Christian missionaries in the treatment of leprosy sufferers, led to perception of the disease as so terrible that only God's servants were capable of tending those affected by it. An alternative explanation, related specifically to Western culture, locates the sources of the stigma in the nineteenth century, when fears evoked by the high prevalence of leprosy among colonised populations gave rise to the racist views that linked the disease with morally inferior people.

In addition, Colombian physicians super-imposed a biblical image of leprosy as the most repellent of all diseases on the special aversion that Western culture of the late nineteenth and early twentieth centuries accorded to "tropical" diseases as exclusively suffered by "inferior people" (Obregon, 1996). For thousands of years, Europeans have represented leprosy sufferers as unclean, tainted, and dangerous. Contact with leprosy has often been equated with moral and physical contamination (Anderson, 1998). An additional approach holds that such outdated views are perpetuated mainly by the sensationalism and dramatisation of the disease in art, literature, and the mass media (Navon, 1998). A different perspective emphasises that the stigma is the product of the compulsory segregation of leprosy sufferers, practiced in many countries since the end of the nineteenth century. Similar claims have been made concerning frightening public education campaigns, conducted in an effort to encourage people with leprosy to seek treatment (Navon, 1998). Diseases are used as metaphors, as adjectives to refer to what is viewed as morally wrong or dangerous. The more mysterious an illness seems to be, the more metaphorical it becomes (Obregon, 1996). However, in some religions and cultures leprosy is not such a stigmatised disease. For example, Muslims believe that every outcome (success or failure) is ordained by God. Consequently, it should not be surprising that ardent followers of this religion do not display resentment towards leprosy patients. This may, perhaps, explain why little stigma has been witnessed in Northern Nigeria where the inhabitants are predominantly Moslem. Also, social

psychologists have proposed that this derives from the norm of social responsibility, which requires that we help those who are dependent (Bainson & Van den Borne, 1998). Furthermore, in accordance with the Buddhist teaching, Thai people held that diseases, like any other event in a person's life, were a result of karma (Navon, 1998). Yet, leprosy was regarded as a fate so cruel that only an accumulation of bad karma from numerous life cycles could account for it. The extremely negative image of the disease is evinced by the fact that its diagnosis led in many cases to suicide attempts, or at least to suicidal thoughts, in spite of the strict prohibition placed by Buddhism on taking one's own life (Navon, 1998). Although the stigmatisation of leprosy is often erroneously attributed to religion, the stigmatisation was present in many cultures where religion had no influence. Chinese folklore, for example, traces the origins of leprosy to soldiers who practiced necrophilia, and not to religion at all (Sabin, 1993).

The role of medical aspects in the stigmatisation of leprosy sufferers

Medical researchers have found a cure for leprosy, and infectivity can be reduced to very low levels with modern multidrug therapy (MDT). The affected persons therefore do not pose a health hazard to others (Raju & Reddy, 1995). The non-infectivity of leprosy, however, appears insufficient in that social stigma associated with the disease is not thereby eliminated (Bloombaum & Gugelyk, 1979). Apparently, correct knowledge about the medical facts of leprosy, for example about its curability and non-infectivity, does not imply the complete removal of the stigma (Raju & Kopparty, 1995).

Appeasing the myths about leprosy – the stigma persists

People often fear leprosy, even after medical treatment (Bower, 2001). For those with the disease, the misunderstandings have therefore been historically overwhelmingly catastrophic (Sabin, 1993). Yet attitudes in many countries toward leprosy sufferers have improved substantially in the past two decades. This renewed attitude can be attributed to both the emergence of effective drug treatments in the

1980s and the influence of a subsequent public health campaign to spread the message that leprosy is curable and not hereditary (Bower, 2001). Another positive change in the last fifty years has been the increase in public education efforts to spread the good news that leprosy can be treated and cured, that disabilities are preventable and that people affected by leprosy do not need to be segregated. However, popular imagination still associates leprosy with ghastly images of disfigured bodies.

In an effort to get rid of the leprosy stigma, some countries have even officially changed the name of the disease to a less stigmatising term. The very name itself is part of the problem and involves pictures of the Dark Ages. Attempts to change the name to Hansen's disease, after the Norwegian who discovered its causative agent, have not succeeded - partly because the description of the disease was prior to Hansen. Leprologists participating in the Fifth International Congress on Leprosy held in Havana in 1948 concluded that the sick should not be called "lepers", but "leprosy sufferers" (Obregon, 1996). There is no doubt about the growth and conveyance of scientific knowledge on leprosy in the last 100 years, however, it seems as if the stigma regarding leprosy persists.

Several studies show that following the successful treatment of leprosy, its negative image gradually faded, and even before that many local communities accepted or only moderately stigmatised leprosy sufferers. On the basis of these findings some researchers suggest that leprosy is not universally stigmatised and that its depiction as the most rejected of all diseases is rather exaggerated (Navon, 1998). In light of these developments, one would expect leprosy's negative image to gradually fade away. However, questionnaire surveys designed to assess attitudes towards leprosy, which were conducted between 1978 and 1983 by the Thai government among representative sections of society, revealed that the disease continued to be perceived as incurable, deforming, and frightening. Moreover, the interviews held within the framework of Navon's (1998) study point to the persistence of the association of leprosy with the figure of the beggar. However, removal of stigma

seems to be a long drawn out process and it also seems to differ from one culture to another (Augustine, Joseph & Rao, 1999).

THE IMPACT OF FACIAL DEFORMITIES ON THE PSYCHOSOCIAL FUNCTIONING OF LEPROSY PATIENTS

In parts of the world where tuberculoid leprosy dominates, affected persons often have only a few cutaneous patches of anaesthesia and some associated paralysed nerves, and there is little stigma attached to the disease. In contrast, gross facial deformity can develop in untreated lepromatous leprosy. The deformity is related to the enormous number of bacilli that infiltrate both the skin, causing it to be thrown up in multiple folds (leonine facies), and the nasal septum, leading to collapse of the nose. The disfiguration is exaggerated by patchy facial nerve involvement and the tendency for corneal opacities to develop secondary not only to bacterial infiltration but also to damage from unfelt foreign objects. The medical profession has already recognised that grotesque facial distortion can elicit strong responses and be a source of stigma (Sabin, 1993). First, social rejection often follows the development of stigmatising lesions of the nose, ears, eyebrows, nerves and so on (Scollard & Skinsnes, 1999). Different parts of the body, especially the face, are thus more vulnerable to stigma than others (Staples, 2003). This phenomenon needs no elaboration since persons with visible physical deformities are often socially ostracised and then reduced to the state of beggars (Anandaraj, 1995).

Since a saddle nose is one of the most dreadful deformities and a significant symbol of leprosy, it often causes serious psychological and social troubles to patients. Since the deformity of a nose is conspicuous, patients usually have some social difficulties as well as physical and mental problems. The impact is perhaps most intense when patients are young and unmarried. Traditionally, surgical treatment has been provided only in leprosy institutions. With the increasing integration of leprosy management in general health care, there is a need for integration and decentralisation of surgical activities. Similarly, surgical correction of deformities of leprosy is most rewarding in improving body image and erosion of stigma, functional

capabilities and reduction of psychiatric morbidity (Ishida, Pecorini, Guglielmelli, 1999). However, in research performed by Staples (2003) to determine what part of their bodies leprosy sufferers would like to change, initial responses were that they would change nothing, that the condition of their bodies was "God's will". With some probing, people said (without exception) that they would first change their faces. The face is physiologically the first point of contact with other people; the most important site "from which visual information on the body state can be conveyed" (Staples, 2003, p. 300). In view of these studies, it is necessary to correct (especially facial) deformities and provide rehabilitation to all the deformed patients (Kopparty, 1995).

THE IMPACT OF LEPROSY IN THE WORKPLACE AND ON THE MOBILITY OF PATIENTS

In a South-African study of leprosy sufferers by Scott (2000), all participants (30) were found to be afraid of losing their work, and 17 did not mention the name of their disease to their employers. Doubt about the productivity of sufferers was the main reason why employers displayed a negative attitude towards the participants. In research performed by Kopparty (1995), of the 150 deformed patients, 86 (57.3%) found their deformity to be a handicap in employment. When the employment of the patients was affected, their family faced economic problems often depriving them of their daily necessities. The problems faced by the families of the handicapped deformed patients were economic and social in nature. The economic problems faced include: loss of main source of income because of loss of occupation; loss of additional source of income; loss of savings and incurring debt to meet the family expenditure (Kopparty, 1995; Tare, 1991). Generally, change in occupation leads to accepting less demanding and less remunerative work resulting in a fall in income that leads to economic problems. Patients also complained that the disease did indeed handicap them in their daily activities. Lack of mobility was a definite handicap to participation in social activities in church, cinemas and dance halls (Scott, 2000). Studies have demonstrated the restoration of dignity, status and acceptance of the affected patients once they are economically rehabilitated (Kopparty, 1995).

THE ROLE OF MEDICAL PROFESSIONALS ON THE PSYCHOSOCIAL FUNCTIONING OF LEPROSY PATIENTS

Leprosy sufferers tend to rely on traditional systems, as well as Westernised medical systems, when they have to deal with their physical symptoms. Regardless of what route they pursue, it is essential that they have to be treated compassionately. In a South African study by Scott (2000), 11 (of 30 participants) first consulted a sangoma before visiting a medical doctor or clinic. The reasons were as follows: belief that a spell had been cast on them, family influences (relatives convinced the patients that they had been bewitched) and the influence of tradition (observations such as "This is our doctor"). In some cases where medical doctors were unable to make a diagnosis, some patients turned to sangomas for advice. Only eight participants stated that they did not believe the medical doctor who told them that they had leprosy. Some participants were of the opinion that the doctors had not imparted the essential medical information to them. In certain cases, a definite fear of the disease among nursing personnel in general hospitals existed. These tendencies led to aggressiveness by some participants. Generally speaking, the participants were very satisfied with the treatment they received from the Leprosy Mission and at Westfort Hospital. This is reflected in the fact that 23 of the participants, after being discharged, requested that a rehabilitation officer or a representative of the Mission should pay them a visit. Only two of the thirty leprosy sufferers had been treated insensitively by rehabilitation officers in their own opinion.

Dr Paul Brand who worked as a medical professional among leprosy sufferers for 50 years, maintains that the greatest skill that medical professionals need is

...to have the ability to put ourselves into the inner place where our patients live. If we learn to share their fears and their hopes; above all we can love them and demonstrate our belief in their true worth, then we shall experience in our own souls the happiness of seeing a new life emerging from what had been misery and despair. We may

recognise that the hope that lights their eye is the living continuity or our hope for them. The faith that energises their progress is our faith. The touch of our hands if felt by them as the touch of God's hand on their lives. The joy they feel had roots in us, and now comes back to enhance our own happiness as well as theirs (Brand, 1995, p. 112).

Patients are maximally conscious of their disability, and of the huge gap between themselves and medical professionals. This is why it is so important for doctors and therapists to rid themselves of their image of distance and power and to be caring and compassionate towards patients (Worboys, 2000). In Dr Brand's encounter with one of his patients, he (Dr Brand) put his arm around the patient's shoulders. The patient started crying and as Dr Brand did not have full comprehension of the man's language, he asked a nursing sister about the patient's response. She replied that nobody has put an affectionate arm around him for years and years, and here was a doctor who behaved as though he loved him. This sister responded,

I have always been grateful to an old doctor who taught me in medical school. He had come back after retirement during the Second World War, because there was a shortage of doctors. I have watched patients who were depressed seem to come alive and hopeful while they talked with that great surgeon. He had broken down the barrier, and they felt like persons rather than patients (Brand, 1995, p. 111).

Medical students and house officers must often struggle to overcome pernicious attitudes evoked by stigmatised disease. Fear of contagion, notions of moral lapse, and metaphorical distortions of certain diseases can interfere with serving the patient's interests (Sabin, 1993).

THE ROLE OF RELIGION IN DEALING WITH PSYCHOSOCIAL STRESSORS

Religion plays a role in the community's attitudes towards leprosy patients. Most Muslim patients believe that leprosy is God's will (Awofeso, 1995). Contrary to other

societies, a diagnosis of leprosy does not entail a moral connotation of blame. In Buddhist doctrine, affliction by the disease, just like any other event in a person's life, is ascribed to karma. Popular belief even attributed it to karma from former lives only, thus releasing leprosy sufferers from personal responsibility for their disease. Furthermore, kindness is regarded as one of the noblest virtues for a Buddhist to possess, and succouring the ill, the poor, and the elderly is considered to be one of the most meritorious acts (Navon, 1996). These religious beliefs limited the extent of the loathing felt for people with leprosy. Negative perceptions of them were also reduced by the Thai cultural codes, which attach special importance to the maintenance of social harmony. In this culture, criticising and embarrassing another person are frowned upon, while the upheld values are consideration, respect for others and acceptance of things as they are. The influence of these religious and cultural values presented the unequivocal definition of people with leprosy as social deviants. The contrast between the repugnance they arose and the values denouncing such feelings was reflected in their ambivalent perception as blameless social deviants, who had to be kept apart on the one hand, but deserved pity and aid on the other (Navon, 1996).

Some Christian patients, however, perceive it as a punishment for sins (Awofeso, 1995). In a South African study by Scott (2000), he established that some of the grief of leprosy patients originated as a result of certain passages in the Bible. Some leprosy sufferers were isolated because members of the community felt that such patients had to be segregated according to biblical injunctions (Awofeso, 1995). New translations of the Bible have also helped reduce some of the special religious significance of leprosy by substituting "skin diseases" for the word "leprosy" in the text (Frist, 2000). In spite of passages in the Bible that might lead to misinterpretation, religion can offer an emotional crutch for many leprosy sufferers (Scott, 2000).

Some cultures place so much value on words alone to convey meaning, thought and emotion that the healing power of touch is underestimated (O'Brien, 2000). When approached by a leper pleading to be healed, Jesus relied not on his eloquence as a

prophet or his persuasiveness as a teacher, but on the simple human gesture of touch. By reaching out to the leper, Jesus made him entirely whole again, not just physically. In the face of social ostracism, Jesus' touch recognised the leper's dignity as a human being. Anderson (1998) maintains that leprosy sufferers would be especially susceptible to the gospel. Coady (2004) remarks that over decades institutionalised patients shuffled, padded and limped to chapels each day to recite the rosary and sing hymns. Coady (2004) cites how one of the new sisters asked a patient what he remembered about Father Joe Sweeney (a priest) in a leprosarium in South Korea. Did he remember the good care he received, the Christian teaching, and the sacraments? "He bought us food that we liked," was the patient's reply. "And he ate with us" (Coady, 2004, p. 31)

Throughout the centuries religious institutions and organisations (like the Leprosy Mission in South Africa) have played a significant role in the care of leprosy sufferers. When it was financially and practically impossible for a family to take care of a chronic leprosy sufferer, he was often placed in the care of monks in Buddhist temples.

OVERCOMING THE STIGMA OF LEPROSY

Encounters with leprosy and its severe stigmatisation, may inspire some leprosy patients to overcome society's obstacles and to achieve more than they might have otherwise (Morrison, 2000). In stories told in a study on hope, and evidenced in rare autobiographies, there are persons with leprosy who define and choose meanings of health and quality of life that may surprise the public (Wang, 1997). These accounts have brought fresh insights and new understandings about people's participation in co-creating health that shapes quality of life on the basis of personal value priorities despite hardships.

Stein, a blind leprosy sufferer, founded *The Star* in 1941-a bimonthly magazine to offer information and to educate people about leprosy. In his autobiography, *Alone*

No Longer: The Story of a Man Who Refused to Be One of the Living Dead!, Stein wrote:

Instead of bemoaning the things that I have lost, I try to make the most of what I have left...for all the bitterness in my experience, there has been equal sweetness. I have missed much in my life. More than half of it has been spent in an institution. I have for years been denied the companionship of family and friends and other blessings that go with good health, but I have gained a great deal. My sense of values has been completely changed. What I thought important before Carville now seems very unimportant. I feel wanted and useful (Stein & Blochman, 1963, p. 335).

Stein in general found his life useful and worthy in spite of his predicament. His view of health and quality of life at that moment reflected his value priorities that had shifted from his earlier years. Many participants in a study on hope (Wang, 1997) in a Taiwanese Leprosarium shared similar views. One of the participants, Ah Fan (pseudonym), changed his view of life and health from feeling hopeless and like the “living dead” to feeling hopeful and worthy despite still living with leprosy. Ah Fan was infected with leprosy at age 12. For the next 10 years, he was confined to home, which he described as a “dark prison.” Life for him was meaningless. He attempted suicide many times and after his last attempt, he decided to leave home. He thought there still might be hope if he left; he might meet someone to cure the disease and to improve his looks. He travelled aimlessly, carrying very few clothes and little money. To avoid being seen by others because of his “ugly” looks, he slept in parks and ate in bathrooms, even though he had money to stay in motels. After entering the leprosarium, Ah Fan worked very hard as a nurse aid while receiving treatment. Despite illiteracy and deformed hands, he spent his days and nights learning how to read music and how to play the organ with his two remaining fingers. Later on, he became a representative and an organ player of the Catholic Church. He totally changed his perspective and forged ahead in a new way to enjoy a hopeful life. While reflecting on his hope for a better life, he said:

I'd like to devote myself to church...Now, I can stand and speak in front of many, many people ...At present, I am a person with hope, I must take firm hold of that ...I do things I enjoy the most. I call my friends up, watch TV, or have a cup of tea. This is called the joy of the life. I feel hopeful (Wang, 1997, p. 145).

To change living “miserably” to living “joyfully and hopefully”, Ah Fan changed his values and committed himself to create a “joyful and hopeful” life, thus changing his health.

Like Stein, Ah Fan’s sense of value completely changed. What was important before, such as curing the disease and improving his looks, had become unimportant. They still live with leprosy, yet they say that they “do not care anymore.” Ah Fan and Stein have chosen and defined their personal meanings of quality of life and health on the basis of what is important at “this” moment in life (Wang, 1997).

CONCLUSION

Leprosy is one of the oldest diseases known to humankind, and for centuries people with the disease have been stigmatised. Perhaps no other human disease, since the periodic outbreaks of plague and the rise of the HIV epidemic, has provoked stronger social responses. Some authors describe the disease as the ultimate in physical disfigurement and negative social consequences, based partly on misconceptions about the medical aspects of leprosy. Furthermore, it is suggested that the stigma attached to leprosy, is universal in all societies. Leprosy can exercise a strong influence on the behaviour of a leprosy sufferer. Where the disease has been present since childhood, it can influence a patient’s behaviour for the rest of his or her life. The high rate of suicidal thoughts among leprosy sufferers highlights the patients’ concept of the psychosocial turmoil created by this disease. A variety of emotions are intensely experienced by leprosy sufferers. Grief appears to be the

first and most general reaction that leprosy sufferers show after a diagnosis of leprosy had been made. In some cases the morbidity becomes chronic, and the incidence of psychiatric conditions is therefore indicated. While men and women are both negatively affected by leprosy, the main extent of impact appears to be more among women in terms of isolation, rejection from spouses, children and relatives, loss of freedom to touch and other restrictions. In the last fifty years, there has been a worldwide effort to de-institutionalise leprosy patients as people realise that segregation is not justifiable for medical, financial or ethical reasons. Leprosy sufferers in general are negative about lengthy institutionalisation. Therefore, hospitalisation can have a negative effect on their view of the disease. It is important that patients should (as far as possible) have the freedom to decide whether they want to be institutionalised or not. More so since hospitalisation implies that the leprosy sufferer is withdrawn from the labour market. Absence from work and the employer's perception about the contagiousness of the disease, proved to be determining factors in deciding whether an employee should retain his or her work. In cases where employment of patients is affected, their family face economic problems often depriving them of their daily necessities. Traditional and Westernised healers can play a major role in the removal of the stigma that leprosy is contagious. Marriage and family ties are all influenced by leprosy. Even where communication between leprosy sufferers and their marriage partners is unrestricted, lack of information (with both partners) can cause wrong perceptions about the disease, which in turn have a detrimental influence on the marital relationship and could in some instances even lead to divorce. If the family can accept the leprosy sufferer after diagnosis, the household members are an indispensable source of support. Erroneous interpretation of the Bible gives rise to stigmatisation, and therefore church teaching should rectify this. In conclusion, a close look at the psychosocial needs of leprosy sufferers in South Africa by Scott (2000) shows that their needs are similar to those of leprosy sufferers in other parts of the world in three ways:

- The need for self-acceptance. Participants' views of life and the way in which they conceptualised the disease are decisive factors for their levels of mental

health. The intensity of emotions experienced by leprosy sufferers immediately after diagnosis underscores how important it is to have emotional support immediately available.

- The need for social acceptance. Of leprosy sufferers who had been married during the period of diagnosis, 40% of men and 30% of women were deserted by their spouses as result of the disease.
- The need for acceptance by the community. The extent to which the psychosocial need of leprosy sufferers will be met depends in part on the way in which they are treated by their support systems. These systems include patients, families and relatives, employers, medical doctors and hospital staff. The information, which is transmitted regarding the medical aspects of leprosy, should be consistent.

In the next chapter attention will be given to 'Sense of Coherence' as a means of dealing with adversity such as leprosy.

CHAPTER FOUR

SENSE OF COHERENCE: A FOCUS ON STRENGTHS

INTRODUCTION

In this chapter, the salutogenic model will be discussed, as well as the salutogenic constructs. A selection of specific salutogenic constructs for this study will then be discussed namely hardiness, locus of control, self-efficacy, potency and learned resourcefulness. This chapter will conclude with a discussion of the social implications of the sense of coherence (SOC) phenomena and the spiritual dimension of SOC.

EVOLUTION OF A NEW PERSPECTIVE

One of the major contributions to the discipline of behavioural health is that of Aaron Antonovsky, a medical sociologist of the Ben-Gurion University of Negev in Israel (Fullard, 1992). In a study in 1965, John Kosa, Irving Zola and Aaron Antonovsky reviewed all empirical studies associated with social class and some measure of disease. The main aim of this study was to identify the stressors in the lives of poor people that underlie their health and illness. The results of this review lead to the publication of *Poverty and health: a sociological analysis*, edited by Kosa, Zola and Antonovsky (1969). The data presented in this publication showed that the objective stressors were important variables in the casual relationship to disease, and that the poor also ended up badly because they had fewer resources to combat these stressors (Antonovsky, 1979; Kosa, Zola, & Antonovsky, 1969). This insight resulted in a turning point in Antonovsky's thinking and marked the development of a new thought:

If two people were confronted by an identical stressor, ... but one had the wherewithal to successfully meet the challenge and the other did

not, how could this situation best be conceptualized? (Antonovsky, 1979, p.3).

Who are the high-stress people who remain healthy, and how do they differ from other high-stress people who become ill?

By working on this question, Antonovsky developed the theory of *breakdown* (Antonovsky, 1972). This theory implied a basic distinction between two problems. Firstly, there is the fundamental question of all medicine: “Why does someone get a particular disease?” In the second place: “Why does someone gets dis-ease, or the notion of breakdown?” The idea entails that there are shared features to all diseases and in the same way, there are common facets to all forms of health. Antonovsky defined these common facets as generalised resistance resources in the case of health, and resistance resource deficits in the case of disease (Antonovsky, 1972; 1979). He described the generalised resistance resources (GRRs) as “...any characteristic of the person, the group or the environment that can facilitate effective tension management” (Antonovsky, 1979, p.99). Antonovsky’s idea of breakdown essentially implied that stress and stress-induced illnesses develop according to the extent that GRRs are deficient, leading to lowered resistance and dis-ease susceptibility (1972; 1979; 1987a).

The most fundamental transformation in Antonovsky’s approach towards health and disease happened during the nineteen seventies when he worked on a menopause-adaptation study of Israeli women (Antonovsky, 1979; 1987a). Antonovsky was impressed by the fact that a substantial proportion (29%) of these women, who were survivors from concentration camps during the Second World War, had maintained good emotional health. Antonovsky found the number who had maintained good emotional health to be impressively large. The obvious question asked was what had given these women the strength, despite their situation, to maintain the capacity to function well and to even be happy, at least on one level (Antonovsky, Maoz, Dowty & Wijisenbeek, 1971). In his seminal book *Unravelling the Mystery of Health:*

How People Manage Stress and Stay Well, Antonovsky (1987c) summarised the impact that the study had upon him as follows:

To have gone through the most unimaginable horror of the camp, followed by years of being a displaced person, and then to have re-established one's life in a country which witnessed three wars ... and still be in reasonable health. This for me, was the dramatic experience which consciously set me on the road to formulating what I came to call the salutogenic model (p. xi).

The theory of *salutogenesis* (which focuses on the origins of health) was published during 1979 in *Health, Stress, and Coping*. This book was widely read and the ideas therein were appealing to a variety of people. Antonovsky's colleague, Leonard Syme, told how *Health, Stress, and Coping* had been written. After each class, Antonovsky would revise one chapter based on class discussion, and he would write a new one for the next class. By the end of the semester, he completed the book. Syme believed that Antonovsky had been so sure about what he wanted to write, that he was able to write a book within ten weeks that forever changed social epidemiology (Lenderking & Levine, 1995). In 1992, Antonovsky remarked that posing the question of salutogenesis constituted his greatest contribution towards generating knowledge (Lenderking & Levine, 1995).

THE SALUTOGENIC ORIENTATION

A very important question seems to be how one remains physically and emotionally healthy in spite of the limitless variety of natural, sociopolitical and psychological stressors to which individuals are continually exposed. "Given the ubiquity of pathogens – microbiological, chemical, physical, social and cultural – it seems to me self-evident that every one should succumb to this bombardment and constantly be dying" (Antonovsky, 1979, p. 13). Since this is clearly not the case, Antonovsky tried to unravel "the mystery of health" and find answers to the question how people manage stress and stay well (Antonovsky, 1987a). With the emphasis and focus on

health creation, rather than disease etiology, the conceptual neologism of salutogenesis from Latin: *salus* (= health) and Greek: *genesis* (= origins) was proposed in contrast to pathogenesis.

According to Wissing and Van Eeden (1997, 2002), general psychological wellness – which implies “health” – is a combination of specific qualities, such as a sense of coherence (SOC), satisfaction with life, affect balance and a general attitude of optimism or positive life orientation. In research performed in South Africa by Cilliers and Kossuth (2002) on the relationship between organisational climate and salutogenic functioning, it was established that the individual’s experience of a positive organisational climate relates to a high level of salutogenic functioning.

Researchers like Strümpfer (1995, 2003) prefer the term “fortigenesis” to Antonovsky’s “salutogenesis”. “Fortigenesis” is derived from the Latin: *fortis* (= strong). According to Strümpfer (1995), the introduction of this construct is not to deny the need to search for the origins of health; but to broaden the search to the origins of psychological strength in general. The term “fortigenesis” is therefore more holistic than “salutogenesis”.

The pathogenic orientation to health

People have been trying to account for the origins of health and illness since the beginning of recorded history. The attempt to account for disease permeates the development of all the great spiritual traditions and religion. Only in the last 200 years have there been attempts to purge meaning from this understanding. In the name of modern science it has been declared that health and illness mean very little. If a body is sick, it is only a consequence of what its atoms and molecules happen to be doing at any given time, which is following the “blind” laws of nature. Meaning is not found in nature, but is read “into health” it cannot scientifically be “read out” of it (Dossey, 1994). It is therefore obvious that, historically, the majority of health-related research has been characterised by a focus on the origin of disease (Antonovsky, 1987b; 1987c). Antonovsky and other theorists began to speak about something

more than molecules. Pathogenesis – the genesis of pathology, an expression of the second law of thermodynamics, when organised entities including human bodies “run down” and become chaotic – was only part of the story (Dossey, 1994).

The pathogenic approach has been primarily concerned with the societal consequences of poor health. From this perspective, illness and disease are seen as contributing towards entropy at all levels of society, while health is seen as simply the absence of illness or disease (Antonovsky, 1987c). Underlying the pathogenic approach to scientific investigation is the basic belief that there are individual, normally self-regulatory, homeostatic processes which may become deregulated (1987c). The focus of pathogenic research has been illness as manifested by the individual. Thus, the pathogenicist seeks and is content with hypothesis conformation derived from the identification of the deviant case. This approach implies a moral imperative to decrease or eradicate individual suffering, which is seen as taking priority over enhancement of health.

Antonovsky has described current Western health care options through the metaphor of “the basis of the downstream focus,” in which he likens contemporary Western medicine to a well-organised, heroic and technologically sophisticated effort to pull drowning people out of the raging river. “Devotedly engaged in the task and often well rewarded, the establishment members never raise their eyes or mind to inquire upstream, around the bend in the river, about who or what is pushing all these people in “ (Antonovsky 1987c, p.2). The pathogenic model therefore fails to account for the apparently healthy state of those individuals who manage to stay well despite the presence of risk factors which often predict poor health. One possible method of accounting for unexplained health found in a pathogenic model may be provided through a salutogenic approach.

The salutogenic perspective

While the pathological orientation attempts to explain why people get sick, and why they enter a given disease category, the salutogenic model disregards the fundamental dichotomy between healthy and sick people. Instead, all people are

viewed as terminal cases. However, all people are also in some measure healthy. The salutogenic orientation studies the position of each person, at any given time, on this continuum ranging from health-ease to dis-ease. The salutogenic orientation therefore poses a radically different question, namely: Why are people positioned towards the positive end of health-ease/dis-ease continuum, and why do they move towards this end? The aim of this perspective could be summed up in the salutogenic question: “How can we explain health rather than disease?” (Antonovsky, 1987a). The advancement of positive health is aimed for by means of understanding those factors that enable health to prosper in the presence of existing stressors.

The salutogenic model focuses on stress and its effects on human health. The term salutogenesis, seen as the antonym of pathogenesis, is meant to emphasise health promotion and disease prevention rather than the pathogenic origins of disease (Antonovsky, 1987a). The notion is that the primary prevention approach is an appropriate instrument for such services supplementing the pathogenic medical model of diagnosis and treatment (Frankenhoff, 1998). An individual’s position and direction of movement along the health-ease/dis-ease continuum are determined by the interplay of opposing forces of environmental threat (e.g. stressors), one’s resistance (e.g. generalised resistance resources), and the strength of one’s sense of coherence (SOC) (discussed later). The central thesis of the salutogenic model is that environmental threats (stressors) are omnipresent in human existence, and even with a high stressor load, many people (though far from most) survive and even do well (Antonovsky 1979; 1987b). Thus the salutogenic question *par excellence* is: Why do some people cope successfully in spite of omnipresent stressors, and others not? The answer to this question may have a generalised impact on physical and psychological health through educational interventions (Wills, 1992).

The idea that underlies the homeostatic view – the removal of stressors or risk factors creates health – contrasts sharply with Antonovsky’s conceptualisation. In his model, dynamic health development is impossible without the challenge of social stressors (Broda, 1994). Therefore, the strengthening of the social system, the

physical environment, the organism and the lower-order systems is of utmost importance. A salutogenic orientation enables the researcher to seek an understanding of the factors involved in individuals who are healthy (Antonovsky, 1987a).

Consciousness can influence the response to external trauma. Hence, there are limits to the extent to which perceptual changes in the individual matter. Sapolsky (1994) points out that attributing undue potential to such individual interventions constitutes poor science and poor clinical practice. It denies the pain of the suffering individual. It should seem obvious that, just because psychological and perceptual factors can influence disease processes, they cannot necessarily determine them. Apart from that - when the individual has the perceptual potential to manage well in unfavourable circumstances - there is, unfortunately, no imperative to change the world (Sapolsky, 1994).

The salutogenic approach is all encompassing and investigates a person within his or her environment (Antonovsky, 1987a). The pathogenic approach to assessment is possibly less encompassing and thus more likely to miss data of great etiological significance. This fundamental difference between the pathogenic and salutogenic approach does not imply that the pathogenic approach is insensitive. The pathogenically-oriented clinician may be as compassionate as his or her salutogenically-oriented counterpart (Antonovsky, 1987c), but by being one of the developers of the biopsychosocial framework and for his concept of salutogenesis, Antonovsky helped break the strong hold of purely physical models of health (Dossey, 1994).

Antonovsky's concept of salutogenesis had to be operationalised (Strümpfer, 1995). In his second book in the area of salutogenesis, Antonovsky (1987c) reported a study that served as the first step in the operationalisation of his construct "SOC", which underpins his theory of salutogenesis. The participants were not selected on health grounds. Persons who met two criteria were nominated for in-depth study:

In the first place, the person was to have undergone severe trauma with inescapable consequences for his or her life: severe disability (eighteen persons), loss of a loved person (eleven), difficult economic conditions (ten), concentration camp internment (eighteen) or recent immigration from the Soviet Union (four). Secondly, the person was thought by the referee to be “functioning remarkably well” (Antonovsky, 1987c, p. 64). Consequently, Antonovsky formulated the fulcrum of salutogenesis, which is the SOC. According to Lenderking and Levine (1995), Antonovsky may best be remembered for his work on the SOC concept. This concept, basically referred to as a preventative orientation, appealed to a number of lay people as well as academics (Lenderking & Levine, 1995).

SENSE OF COHERENCE

Antonovsky (1987a) suggested that SOC is the key determinant in the maintenance of health and breakdown. In his salutogenic model, individuals with a strong SOC are seen to have the ability to perceive stressors as manageable, meaningful and comprehensible. A positive outcome of an encounter with a stressor is basically dependent on the successful management of the stressor and the presence of a strong SOC (Antonovsky, 1996b).

Antonovsky (1979) conceptualised SOC as one among several “generalised resistance resources” (discussed later) which play an important role in the maintenance of health. Antonovsky claimed that individuals who have a strong SOC, are less likely to succumb to microbiological and psychological pathogens than those individuals under equal life stress, but whose lives have less coherence. Antonovsky (1993) characterised a SOC as being: “...the core of the organization of a complex human system for successful processing of information and energy, and makes conflict resolution possible” (p. 972). Furthermore, Antonovsky (1979) provided the following more comprehensive definition:

The sense of coherence is a global orientation that expresses the extent to which one has a pervasive, enduring, though dynamic feeling

of confidence that (a) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; (b) the resources are available to one to meet the demands posed by these stimuli; and (c) these demands are challenges, worthy of investment and engagement (p.123).

The SOC and generalised resistance resources

The adequacy of resources available to the individual is of crucial importance in determining whether tension states will lead to pathogenic stress or salutogenic strengthening (Johnson, 1995). According to Antonovsky (1987c), in addition to resources which are inherent in the nature of the stressor, there are broad categories of resources which promote successful tension management. Antonovsky (1979) argues that through life experiences, individuals develop "generalised resistance resources" (GRRs), which are seen as any characteristic of the individual, group, subculture or society that assists in avoiding or fighting a wide variety of stressors. A GRR is any one of a broad range of resources that neutralises stressor life events that individuals frequently encounter (e.g. chronic stressors, major life events, acute daily hassles) or that promotes successful tension management (Wolff, 1999).

A person who often experiences the availability of GRRs, seems to develop the personality construct (the SOC) (Antonovsky, 1979, p.143). The role of this construct (and other salutogenic constructs) is three-directional: firstly, by mobilising the GRRs at the individual's disposal, a strong SOC can prevent the individual from being subjected to stressors. Secondly, it allows the individual to define certain stimuli as being welcome. Thirdly, the SOC plays a major role in the individual's movement on the health ease/dis-ease continuum. There seems to be a feedback loop from the GRRs to strong salutogenic constructs, which feeds back to the GRRs which, depending on previous experience of overcoming stressors, enhance the salutogenic construct. In turn, a strong SOC mobilises the GRRs at the individual's disposal in order to avoid or overcome stressors, with such experiences reinforcing the SOC in a feedback loop. In addition to the mobilisation of the individual's

generalised resistance resources (Antonovsky, 1987c), successful coping with tension, stressors, or both depends on an individual's SOC as a whole. The availability of GRRs is an important factor in determining whether a stressful situation will result in significant weakening of the individual's SOC, which in turn, has negative or neutral health effects (Antonovsky, 1987a, 1996a; Sullivan, 1993).

The development of the SOC theory was sparked by the observation that certain commonalities existed between different GRRs (Antonovsky, 1996b). The GRRs refer to any properties of a collective or a situation which facilitates successful coping with the inherent stressors of human existence (Antonovsky, 1996a). Antonovsky (1979; 1987a) divided the GRRs into the following categories:

- Artefactual properties (e.g. money, food and shelter).
- Physical and biochemical properties (e.g. immunological strength and neurological adaptability).
- Cognitive and emotional properties (e.g. knowledge, intelligence and identity).
- Valuative-attitudinal properties (e.g. cognitive appraisal habits, flexibility and farsightedness).
- Interpersonal-relational properties (e.g. social support and social commitment).
- Macro-cultural properties (e.g. beliefs, religions, rituals, norms and values embedded in a larger culture).

The commonality among all the GRRs is that they all strengthened repeated life experiences which enabled the person to see the world as "making sense" in a cognitive, instrumental and emotional manner (Antonovsky, 1987a; 1996a). This led to the emergence of the SOC construct (also referred to as a sense of control), a generalised orientation towards the world which perceives it, on a continuum, as comprehensible, manageable and meaningful (Antonovsky, 1996b). The aforementioned three concepts represent the three components of the SOC and together serve as an operational SOC construct:

- Comprehensibility

Comprehensibility entails the extent to which one perceives the internal and external stimuli as making sense. In information systems theory terms, it refers to the ability to perceive stimuli which bombard one from the inner and outer environments, as information rather than as noise. Information implies that the stimuli are perceived and interpreted as clear, structured, consistent and ordered (Antonovsky, 1987a; 1993a).

The person high on the sense of comprehensibility expects that the stimuli he or she will encounter in the future will be predictable, or in the case of surprises, that they will be orderable and explicable. Antonovsky (1987a) highlighted the fact that the challenges with which the person is confronted, are not always desirable. Death, war and failure can occur, but the person high on comprehensibility understands the challenges and makes cognitive sense of them.

- Manageability

The second component of the SOC is manageability. This refers to the extent to which the individual perceives and believes that resources at his or her disposal are adequate to meet the demands posed by the stimuli or challenges with which he or she is confronted (Antonovsky, 1987a; 1996a).

These resources may include one, or a variety of, GRRs. It also refers to resources under one's own control or to resources controlled by legitimate others (e.g. family, friends, colleagues, a physician, history or God) (Antonovsky, 1987a). The person high on the sense of manageability will believe that resources to cope are available and will not feel victimised by events (Antonovsky, 1987a; 1996b). He or she will be less likely to deny them and more likely to maintain health by avoiding self-destructive activities such as substance use. He or she will be more likely to maintain health by creating and executing efficient plans of action (Levenstein, 1994).

- Meaningfulness

The third component of SOC, meaningfulness, is seen by Antonovsky as a motivational element. Life events that are viewed as challenges worthy of emotional investment and commitment are seen as meaningful. A strong component of meaning would indicate that life makes sense emotionally, that at least some of the problems are synergistic, but of unequal salience (Antonovsky, 1987a; 1996a). Although initially comprehensibility was considered the most integral component of the SOC, Antonovsky (1987c) has more recently come to view meaningfulness as being most critical. Without meaningfulness, Antonovsky believes strengths in comprehensibility or manageability are most likely to be temporary. For an individual with a meaningful life, the resultant commitment and caring provide an advantaged access to gaining understanding and resources. Comprehensibility follows in importance, as high manageability is contingent on understanding (Antonovsky, 1987a; 1996b).

In short, the three components of the SOC each represent different dimensions of coping with stressors, stimuli or challenges. Whilst the comprehensibility component represents the cognitive dimension of the SOC, the meaningfulness component represents the emotional dimension. The instrumental or resource dimension, in turn, is represented by the manageability component of the SOC (Antonovsky, 1987a; 1996b).

Having formulated the construct of the SOC, Antonovsky began to try and find ways of operationalising it. His approach to this process was heavily influenced by Louis Guttman's method of facet analysis. Antonovsky developed a highly refined questionnaire which consisted of a list of 29 questions. He called it "The Orientation to Life Questionnaire," which measures the three core components of the SOC (Antonovsky, 1993b). Several hundred studies using the SOC measure have been carried out around the world, most of which document that SOC indeed heightens chances of distress-resistance and good mental and physical health (e.g. Coe, Romeis, Tang & Wolinsky, 1990; Sagy & Antonovsky, 1990; Schafer, 1996).

STRENGTH AND DEVELOPMENT OF THE SOC

Wolff (1999) states that the strength of an individual's SOC is central to the regulation of the everpresent tension or psychophysiological response generated by omnipresent pathogenic stressors (life's events and challenges). Individuals with a strong SOC would avert the transformation of tension to stress. The person with a strong SOC will be motivated to see the task as a challenge and to search for appropriate resources. He or she will have more confidence that performance outcome will be reasonable. Thus, assuming that the task is within the boundaries of what matters to the person, it is indeed likely that there will be some contribution of the SOC to outcome (1987c). Thus, SOC is the major determinant of the position and movement of an individual's state of wellness along the health-disease continuum (Antonovsky, 1985, 1987a, 1993a, 1996b). In contrast, it is more likely for a person with a weak SOC to interpret stressors as threatening and anxiety provoking (Antonovsky & Sagy, 1986). Moreover, an individual with a weak SOC tends to experience more distress and anger when confronted with stressors, and is more likely to report minor stressors as a chronic source of stress (Antonovsky & Sagy, 1986; Holm & McSherry, 1994). In comparison, a person with a strong SOC will regard stressors as a personal challenge "worthy of engagement" and therefore adopt attitudes and engage in behaviours which promote health.

An understanding of the development and maintenance of SOC is necessary in order to determine the effects of SOC on health outcomes (Wolff, 1999). Antonovsky conceptualises health as an evolving continuum. Acknowledging that we are all "terminal cases," the ideal is to move towards the healthy pole of this continuum. In Antonovsky's model, this is accomplished through development and strengthening of the SOC and the GRRs (Antonovsky, 1987c). He argued that an abundance of GRRs will have "consequences not only for the emergence of a strong SOC, and therefore health, but for other areas of well-being too" (1987c, p. 181). He expressed the expectation that there would be positive correlations between SOC and many facets of well-being, since these GRRs also directly promote well-being. There are various routes from GRRs to well-being (Strümpfer, 1995). First, there is the indirect route of GRRs leading to the SOC, but with health, in turn, having a

positive effect on well-being. The second route mentioned by Antonovsky is directly from GRRs to well-being. A third, is that the SOC could be directly related to other aspects of successful living like effective marital, parental, and other interpersonal relationships, but probably also having effects on community involvement, religious expression, economic and political functioning. One could also expect that a person with a strong SOC would come out of a developmental transition (mid-career or retirement) strengthened by the experience. All of these would then contribute to general well-being (Strümpfer, 1995).

The relationship between GRRs and SOC is thus dynamic, catalytic and reciprocal. In the development of SOC, an individual's perception of available GRRs intensifies his or her SOC. Thus, repeated exposure to various stressors life events (and the successful management of those events) results in the development of GRRs and consequently strengthens an individual's SOC. A strong SOC enables an individual to mobilise whatever GRRs are at his or her disposal (Antonovsky, 1987a). In a state of tension, a strong SOC will enable a person to mobilise GRRs, which promotes the further development and reinforcement of strong SOC (Sullivan, 1993).

The development of SOC is also rooted in the sociocultural and historic context of one's life (e.g. childhood experiences, social roles, idiosyncratic factors, and an element of chance) (Sullivan, 1993). Child-rearing patterns and subcultural or cultural patterns of social organisations develop GRRs. Socialisation provides the opportunity to develop a certain degree of SOC. During the family socialisation process, an infant is exposed to stimuli, and the nature of the response (e.g. positive or negative) brings about a set of experiences that leads to the development of meaningfulness. At this time various sociocultural factors and personality characteristics (e.g. social class, gender, genes, and idiosyncratic fortune) influence the development of an individual's SOC (Antonovsky, 1996b).

Exposure to traumatic life events during childhood is a strong predictor of SOC. Stressors before adulthood are the most influential in the development of SOC. Participants who encountered childhood stressors such as parental divorce, physical

abuse and parental alcohol or drug use, were most likely to have a weak SOC as adults. The effect of stress on SOC, specifically childhood stress, could be minimised by having quality social support. Although participants who experienced childhood stressors were more likely to have a weak SOC, the residual effect of these life events can be buffered by having someone to confide in and to make them feel loved.

Antonovsky (1996b) suggested that the strength of an individual's SOC stabilises somewhere along the SOC continuum approximately around the age of 30 years. He argues that by 30 years of age most people have experienced the normal work and family situation of the culture and subculture (e.g. decision making, job role, respect, power, allocation, and load balance). Thus, for the most part, there are no major changes in the quality of experiences and individual encounters that will significantly affect the further development of SOC. That is, the magnitude of change will be considerably less than that observed in the first 30 years of development.

Antonovsky and his colleagues realised that further empirical validation of the SOC was needed. Many ideas about the concept remain untested. For example, a crucial question is the extent to which the SOC develops and changes over the course of a lifetime, and whether psychological or social interventions can strengthen it (Lenderking & Levine, 1995). Other questions are whether SOC is an alterable psychological characteristic or whether it is inborn and static? Also - whether there is a variable contribution made by the component elements of SOC to health outcomes?

THE DEVELOPMENT OF THE SOC OVER THE LIFESPAN

Antonovsky indicated that the shaping of the SOC involves more than just intra familial personality-shaping experiences. It is also a product of socio-cultural and socio-historical influences. He believed that "there are many cultural paths to a strong SOC" (1987b, p.94). He explained the development of the SOC through major life stages in order to map the strongest determinants of and influence on the three components of SOC. Development during infancy and childhood, as well as

adulthood will be discussed here as it seems to be most relevant for the participants in this study.

Infancy and childhood

Comprehensibility seems to be the result of stable life experiences provided by the major attachment figures during infancy and childhood. Antonovsky refers to the work of Bowlby (1969) and Boyce (1985), who believe that such attachment figures provide the human child (in his or her interaction with the environment) with stable, consistent responses. Daily the child tests the hypothesis that there is consistency, continuity and permanence. Over time, then, the child becomes convinced that his or her world can be counted on not to be constantly changing. The ability of the child to structure reality is limited. To the child, structure is what is already there and is comprehended and appreciated. This implies that if structure is absent, comprehensibility is very low.

Meaningfulness implies the quality of the response which the child elicits from this structured environment, and even more importantly, whether this response is, as Antonovsky (1987c) puts it, “embedded in positive affect” (p.97). Coldness, hostility and disregard, even when obvious physiological needs are met, carry a message of devaluation.

Manageability for the child refers to the balance of demand placed on the child on the one hand and the demands made by the child on the environment on the other hand. This implies, Antonovsky (1987b) argues, that the

underlying dimension of the relationship between the child and his or her social world is power, inevitably unequally distributed. The child's vulnerability and dependance are still quite extreme, providing great motivation to begin acquiring the behaviours, skills, attitudes and values appropriate to establish a social identity, to knowing one's place (p.98).

If the child wants to do something, the response he or she gets can be one of four kinds: being ignored, refused, channelled or encouraged and approved (Antonovsky, 1987c). If too many of these four responses are present, an overload is produced. However, a balance in the response types creates a strong sense of manageability.

Adulthood

The experiences of childhood are reinforced or reversed in adulthood with long-range commitment to persons, social roles and work (Antonovsky, 1987c; 1996b). The adult SOC is influenced by different factors, and Antonovsky (1987c) discusses the housewife and the paid worker as examples of adults whose SOC are influenced by such factors. He regards the typical environment of the housewife as relatively consistent and predictable. The only major problems she may expect are those of overload, where there is never enough time and energy to do everything that must be done, or underload, where one's life is so structured that one's skills, abilities, interests and potential have no channel for expression. Antonovsky (1987c) states, however, that overload remains the major issue as chronic acute overload without adequate opportunity for rest, impinges on the sense of manageability.

Antonovsky (1987c) identifies certain crucial variables summarised briefly under the headings of the components of the SOC:

- **Comprehensibility:** Consistency implies the degree to which one's work situation allows the clarity of seeing the total picture and one's place in it. It also involves job security and open communication and feedback concerning social relations in the workplace.
- **Manageability:** Load balance has to do with the availability of resources to the individual to get the job well done and the degree to which the job situation allows the worker to develop his or her full potential.
- **Meaningfulness:** Participation in the decision making processes at work that affect one's working conditions and one's joy and pride in one's work, is of importance. Social valuation, as expressed in equity of rewards and decision latitude with respect to work itself seem significant.

Despite the importance of work as a major role activity, Antonovsky (1987c) is quick to point out that each of us occupies several roles in society, each of which implies a different set of life experiences relevant to the SOC.

DEMOGRAPHIC VARIABLES AND THE SOC

Early in 1990, Antonovsky sent letters to approximately 100 persons to request information on the salutogenic model and/or to urge them to use the SOC questionnaire in their research. In exchange for use of the questionnaire, researchers were asked to send the results back to him (Johnson, 1995). An update from Antonovsky (1991) contained normative and psychometric data on the SOC questionnaire. Information was received from several geographical locations, including the United States, Canada, Denmark, Switzerland, and Australia. The questionnaire has been translated into thirteen languages. The information provided in the update shows that males generally have a slightly higher score on the SOC questionnaire than females across the sample studied. Other demographic variables such as age, education and income are either not reported or the results are ambiguous. One study by Antonovsky and Sagy (1986), reports that stability of community, older age and male gender were significantly related to higher SOC scores in adolescents. Antonovsky (1985, p.122) suggests that adulthood will show an increasing disparity in the strength of the SOC between those who “embark on this period of life with a strong SOC and those with a moderate SOC, and an even greater disparity between these and those with a weak SOC.” Another important factor relating to the strength of SOC seems to be social class. Antonovsky (1987c) feels that social roles lead the individual to see the world in a particular way. Available alternatives and choices, planning, self-action and interpretation of life events are significantly influenced by social status. People, because of their social location, continually have repeated types of experience, and over time come to see the world differently than those in other social locations. Socially structured conditions therefore seem to directly affect the SOC (Antonovsky, 1979). Antonovsky relates the SOC to social class and to societal and historical conditions,

which, in determining the GRRs available to people, establish prototypical patterns of experience that determine location on the SOC continuum. The stressors that inhibit the SOC and the GRRs that enhance the SOC, are far from being randomly or equally distributed in all communities (Antonovsky, 1987c).

Calnan and Moss (1984) found that the higher the level of education of women, the more likely they were to engage in health promotion practices. Pender, Sechrist, Stromberg & Walker (1990) established that expressed interest in preventive and promotive care, post-high-school education and low life stress were the best predictors of intention to use preventive and promotive health services. Poor health behaviours may be part of a lifestyle orientation reflecting a limited ability to anticipate and cope actively with problems.

It appears that although inferences can be made that certain demographic variables of age, income, gender, education, race and religion may be related to level of SOC, empirical validation has not yet been established.

SALUTOGENIC CONSTRUCTS

Antonovsky (1987c, p.33) said that six years after he had developed his salutogenic model, he noticed 'echoes' of his ideas everywhere. He criticised a number of scientists (Johnson, 1995) who "have written at some length and whose ideas are clearly spelled out and is in considerable compatibility with mine" (Antonovsky 1987c, p.34-35). In his writings he carefully compared and contrasted his approach with the social-psychological formulations of these theorists and researchers (Lenderking & Levine, 1995). The compatibility that Antonovsky referred to is that they, who all did their research in the field of stress and coping, also focused on successful resolution of stressors and a return of health. With reference to his own concept of the SOC, Antonovsky (1991, p.65-69) identified other constructs which could also serve as salutogenic strengths combatting stressors. Antonovsky (1991) included Bandura's self-efficacy, Kobasa's hardiness and Rotter's locus of control in his list of salutogenic strengths. The list of salutogenic constructs has been

extended since Antonovsky's original identification of the above constructs. Therefore, the learned resourcefulness (LR) construct of Rosenbaum, has been included (Strümpfer, 1990). This construct includes not only beliefs, but also skills which all individuals learn from birth. However, what the different constructs have in common is that they focus on how the individuals characteristically cope with stressors and still remain healthy. The constructs focus mainly on factors such as the ability to control and resolve stressful situations successfully. They include a generalised set of beliefs about "oneself and about one's world, which shapes one's appraisal of a given stressor situation" (Antonovsky 1991, p.69). The constructs share the notion that these personality orientations facilitate successful coping and thus contribute to health (Antonovsky 1991). Those who manage the circumstances of their life, seem to have resilience in the face of assault from outside forces. Such resilience includes an ability to maintain health in an environment that is not always conducive to it (Harman, 1994).

SELECTION OF SPECIFIC SALUTOGENIC CONSTRUCTIONS

As mentioned above, a number of salutogenic constructs have developed since the introduction of Antonovsky's model. As mentioned above, a number of salutogenic constructs have developed since the introduction of Antonovsky's model. Some of these constructs proved to be relevant in terms of the way some leprosy sufferers are coping. The following salutogenic constructs are regarded as relevant within the context of this study:

Hardiness

The concept of "personality hardiness" or the "hardy personality" was developed by Suzanne Ouellette Kobasa and her co-workers, at the University of New York (Strümpfer 1990, p.269). Kobasa (1979a) suggests that there has been an extraordinary amount of research since the late 1950s on individuals who fell ill following their encounter with stressful life events. However, those who deal with serious and frequent stress without suffering any change in their physical and

psychological well-being have gone relatively indiscernible. The result is that the popular media have concluded that the case for stress and illness connection is settled. It is thus true that if one wants to stay healthy, one has to avoid stressful life events. Kobasa & Pucetti (1983) believe that the coping style of some individuals consists of turning stressful events into possibilities and opportunities for personal development. In the evaluation of stressful life events, people with hardy personalities find opportunities to exercise decision-making, set goals and complete other complex activities that they appreciate as important human capabilities (Bennishek & Lopez, 1997; Bradley & Klag, 2004; Harrison, 1997; Huang, 1995; Lindberg, 2002).

Kobasa's (1982) hardiness concept was sparked by the identification of participants with high stress scores who were not getting sick. Her studies provide a basis for understanding how individuals can encounter great stress and still be healthy. Kobasa and her co-workers from the City University of New York studied a group of middle-and upper-level managers for three years, monitoring their levels of stress and their incidence of illness (Fullard, 1992). They were able to identify two groups: (1) a high-stress/low-illness group; (2) a high-stress/high-illness group (Kobasa, 1979a). Kobasa used the term "hardiness" to describe those participants who were able to withstand stress and illness. Her results indicate that "hardy" participants differed from those who became ill in that they shared a personality style consisting of interrelated orientations of commitment, control and challenge (Kobasa, 1979a). Persons high on hardiness involve themselves in whatever they are doing (commitment), believe and act as if they can influence the events forming their lives (control), and perceive change to *not* only be normal but also as a stimulus to development (challenge) (Kobasa & Maddi, 1984). Brief discussions of these orientations follow.

Commitment

High commitment generally implies being curious about and interested in activities, things and people (Kobasa & Pucetti, 1983) and having a strong sense of

commitment to self (Fullard, 1992). A person with high commitment has an approach to life that is marked by curiosity and a sense of purpose, and he or she believes in the truth and value of who he or she is (Orr & Westman, 1990). As far as cognitive appraisal is concerned, committed persons have a generalised sense of purpose that allows them to identify with and find meaningful the events, things and persons of their environment.

Control

Control refers to the belief that individuals can influence their life experiences (Oulette, 1993). The “hardy” individuals demonstrated an internal locus of control over their lives (Fullard, 1992). To be in control seems to imply a tendency to feel and act as if one is influential, rather than helpless, in the face of the varied contingencies of life. Control enhances stress resistance, and in terms of coping, a sense of control leads to actions aimed at transforming events into something consistent with an ongoing life plan (Kobasa, 1982).

Challenge

Kobasa (1982) regards challenge as essential in perceiving life changes to be the norm rather than the exception, and in seeing change as a stimulus to growth rather than a threat to security. Kobasa (1979b) suggests that individuals who feel positive about change are catalysts in their environment. They regard change as an important challenge to development (Kobasa & Pucetti, 1983). Challenge seems to colour events as stimulating rather than threatening.

Locus of control

Locus of control is likely to be the most cited construct in psychology and most often used in empirical studies applied to coping, health and well-being (Antonovsky, 1991; Rotter, 1989). The concept of the locus of control was developed by Julian B. Rotter at the University of Connecticut and was introduced for the first time in his classical paper “Generalised expectancies for internal versus external control of

reinforcement” (Rotter, 1966 p.1). This construct reflects the degree to which individuals believe they have control over events in their lives (internal locus of control) versus the degree to which they believe they are victims of fate, external circumstances and/or forces (external locus of control). People with an external locus-of-control seem to fail to see a connection between personal behavioural choices, well-being, and quality of life. They believe that life is determined by the lot into which they were born and by powerful others who restrict their upward mobility.

Rotter (1966; 1992) believes that reinforcement, such as reward or gratification on preceding behaviour, motivates behaviour and depends, in part, on whether the person perceives the reward as contingent on his or her own behaviour independent thereof. If the person does perceive the reward as contingent upon his or her behaviour or relatively permanent characteristics, it is termed a belief in internal control. A healthy sense of independence is therefore necessary in order to believe that one’s actions make a difference in one’s future.

Antonovsky (1991, p.78-87) analysed Rotter’s locus of control, and although he maintains that “one searches in vain for any systematic analysis of the structural origins of an internal locus of control”, he places the structural origins under four headings: internality as a reflection of the objective situations; internality and culture; the concept of powerful others and responsible versus defensive internality. These structural origins will now be briefly described:

Internality as a reflection of the objective situation

Antonovsky (1991) postulates that there is a close relationship between an individual’s locus of control and his or her objective situation. When an individual’s world is overwhelmingly controlled by hostile powerful others, as in concentration camps, then, because it is truly more functional in the long run, he or she comes to have externalised beliefs. Such beliefs thus seem to facilitate survival. Rotter (1992) confirms that objective situations such as severe aversive or traumatic events clearly form part of the origin of locus of control, but he emphasises that the attribution of external or internal causality involves more than mere expectations that an individual can or cannot control events.

Internality and culture

Some so-called “traditional” cultures condemn internality as understood in Western society (Antonovsky, 1991). This is often caused by rules laid down by culture with the subsequent result that individuals believe that if they follow the rule, things will work out well. However, in some cultures there is indeed room for the individual to modify his or her environment and fate (Antonovsky, 1991, p.83). There does seem to be some sort of relationship between the individual’s locus of control and how he or she views the world (Rotter 1966, p.4).

The concept of powerful others

There seem to be a definite link between culture and the “powerful others”. Individuals often feel unable to control their own destiny because “they see themselves as a small cog in a big machine and at the mercy of forces too strong or too vague to control” (Rotter 1966, p.3). According to Antonovsky (1991), there are some family structures, religions and health care settings that encourage proactive or passive behaviour. They claim that God, parents or the doctor have special knowledge or authority. Growing up and living in such socio-cultural settings might well foster strong “powerful others” beliefs, which correlate positively with externality.

Responsive versus defensive internality

Here the following question is relevant: “Which is the cognitive foundation of internal well-being - a sense of personal responsibility or a sense of self-justification?” (Antonovsky 1991, p.85). In this sense, internality could facilitate coping with stress because it means taking credit for good outcomes while rejecting blame for unfortunate ones. It could also do so because it expresses a willingness to assume responsibility, regardless of the outcome. However, the absence of control over outcomes could enhance externality (Antonovsky 1991, p.85). Then there are the defensive externals who are individuals who verbally give external reasons for past failures, but who clearly act as if their behaviour will determine outcomes (Rotter, 1992).

Antonovsky (in Lenderking & Levine, 1995) had reservations about the idea that the internal was necessarily more desirable. Antonovsky (1987b) states that Rotter has a fundamental mistrust in power being in the hands of other people. Antonovsky (1987b) posits that a high SOC can easily derive from a feeling of certainty that higher forces (God, the government or my husband) are in control and will assure a predictable, safe environment. He regarded this view as a culturally narrow formulation but, Rotter himself, was careful to point out that an internal orientation was not more desirable across all cultures or social situations.

However, given the extensive evidence from the clinical, experimental, health and occupational arms of psychology, it could be assumed that personal control and control beliefs play an important role in mediating stress experiences and facilitate functional effectiveness (Biley & Smith, 1997).

Self-efficacy

A concept that is similar in many aspects to Antonovsky's SOC, is that of self-efficacy (Dreher, 1995). This construct was elaborated by Albert Bandura from the Stanford University, California (Antonovsky, 1991). Self-efficacy refers to the belief that one can perform a specific action or complete a task (Bandura, Caprara, Barbaranelli, Gerbino & Pastorelli, 2003). According to Bandura (1982) individuals do not behave optimally, even though they know full well what to do. Thus, self-efficacy is concerned with how individuals judge their capabilities and how, through their self-perception of efficacy, they influence their behaviour and motivation (Dreher, 1995). The basic phenomenon being addressed relies on individuals' sense of personal efficacy to produce and regulate events in their lives. Ultimately, self-efficacy refers to confidence in being able to perform or refrain from specific behaviours. It is thus a key regulatory mechanism in determining human action and coping (Knight, Laudet, Magura, Mahmood, Rosenblum & Vogel, 2003). For example, when older patients with chronic diseases experience greater self-efficacy, they get worse less rapidly. Research done by Lorig (1989) on arthritis

patients showed that physical improvements were not linked to increases in any health-promoting behaviours. Instead, they were linked to increases in self-efficacy.

It is interesting to note that Antonovsky (1991) postulates that Bandura's work is seldom cited in stress literature, as his primary concern is to advance theoretical understanding of the principles governing human behaviour related to task performance. Bandura (1977) claim that it is, however, important to point out the self-efficacy theory emphasises the enhancement of coping behaviour through perceived efficacy. Bandura (1988) elaborates by stating that self-efficacy is the individuals' belief in his or her capacity to mobilise cognition resources and to take action to exercise control over task demands. The question to be asked for the purpose of this research is: "What are the sources of the individual's capacity to cope with stressors?" According to Bandura (1981), the answer is in the fact that individuals possess unique capacities such as symbolising, vicarious learning, fore-thought, self-regulation and self-reflection. By using these capacities individuals can achieve high levels of self-efficacy in five ways, namely performance attainments, vicarious experiences, verbal persuasion, social influence and psychological state.

- Performance attainments

"Performance attainments" refers to "doing something competently" (Antonovsky, 1991). The mastery experience, will be determined not only by the availability of appropriate sources to be successful in that activity, but also by the absence of or barriers to engage in a given activity. This experience is a source of information to build self-efficacy.

- Vicarious experiences

To see others succeed by sustained efforts raises one's beliefs about one's own efficacy (Bandura 1988). According to Antonovsky (1991, p.76), "the performances of those with whom we associate in our daily lives and their relative statuses are guidelines for most of us, most of the time, for what we believe we can do".

- Verbal persuasion and social influence
Bandura (1986) focuses on the decisive role of those who attempt to persuade others about their capabilities. When a persuader is an expert in the matter, his or her credibility is easily accepted. If the persuader is far from the reality, his or her efforts are fruitless. Persuaders also have a normative function such as giving the message: "This is what we expect of people like ourselves or people like us should not be able to do this" (Antonovsky 1991, p.77). Thus, the crucial issue conveyed by the mass media reference groups is that societal norms can only be ignored at one's own peril (Antonovsky, 1991).
- Psychological states
Emotions like tension, fear or anger seem to bring the memory network into play. This is particularly true of anxiety and stress reactions to unfamiliar or potentially aversive events. Perceptions of self-efficacy, however, affect emotional reactions as well as behaviour. For example, cognitions of hope are generally defined as positive expectations for the future. The installation and maintenance of hope is believed to be important to the level of coping in a stressful situation (Knight, *et al.*, 2003). Everyone has a history of emotions, and if this history is one of consistent association between the emotion and coping success, arousal in the new situation is likely to be predictive of high self-efficacy. Emotions result from real, anticipated, recollected or imagined outcomes of power and status relations. Thus emotions may be the proximal source of self-efficacy information.

Learned resourcefulness

Michael Rosenbaum, a psychologist at Tel-Aviv University, formulated the term-learned resourcefulness (LR), which is related to performance in the face of stressful situations. This construct is defined as a set of skills for regulating internal events such as emotions that might otherwise interfere with the smooth execution of target behaviour. Previous research suggests that people high in LR deal more effectively with experimentally induced stress, preventing that stress from interfering with their cognitive performance, such as when solving mathematical problems (Akgun &

Ciarrochi, 2003; Rosenbaum, 1980; Rosenbaum & Jaffe, 1983; Rosenbaum & Palmon, 1984). LR (which is stable across time) describes the belief of individuals, and also the skills and self-central behaviours, which all people learn in different degrees through informal training from the moment of birth (Strümpfer, 1990). Thus Rosenbaum and Jaffe (1983, p.216) define LR as

an acquired repertoire of behavioural skills (mostly cognitive) according to which a person self-regulates internal responses (such as emotions, pain and cognition) that interfere with the smooth execution of a target behaviour.

According to Cilliers and Coetzee (2003), LR helps the individual to understand or her environment and to control his reactions to stressors, and to see these as worthy challenges. For purposes of this research two aspects should be highlighted namely LR as a personality repertoire and LR as self-controlled behaviour.

- LR as a personality repertoire

LR to Rosenbaum (1988;1989) is a set of complex behaviours, cognitions and affects that an individual uses when confronted by a situation that asks for self-control. The repertoires are not only in constant interaction with the person's physical and social environment and are triggered by many situations, but also provide the basis for further learning. Individuals may differ in the extent to which they have acquired the basic behavioural repertoire of LR. The resourceful individual may employ various repertoires to minimise the effects of his or her anxiety, while the less resourceful individual may succumb to his or her anxiety.

- LR as a self-controlled behaviour

Rosenbaum and Ben-Ari (1985) claim that LR is an effective repertoire of self-controlled behaviour. By using acquired repertoires of behaviours and skills, the individual self-regulates internal responses that interfere with desired responses. Effective self-control behaviour may assist participants to sustain

goal-directed behaviour even when external reinforcers are not available or are non-contingent and negative.

MACROSOCIAL FACTORS

Kaplan and Salonen (1990) suggest that cynical mistrust, impaired interpersonal relationships, helplessness and depression are more prevalent among those with lower income. Antonovsky would point at social conditions and say that being unemployed, poor, disenfranchised or consistently discriminated against, is enough to drive any sane person towards fatalism, depression or hostility. Antonovsky criticised the current tendency to view feelings and attitudes (such as hostility or depression) as “properties of individuals, with little concern for their social and developmental roots” (Harman, 1994). Thus, Antonovsky (in Sapolsky, 1994) points out that one must appreciate the societal context in which a person is functioning. In normal development, favourable experiences from childhood on slowly build up a salutogenic personality orientation (Harman, 1994). However, people growing up in a poor urban area may not experience such a salutogenic milieu. The fact that most of the participants in this study are poor and living in low socio-economic areas, is an important factor that should not be overlooked. Furthermore, the participants grew up in the apartheid era, and some were exposed to racist treatment. As Dreher (1995) suggests, racism is a health issue, apart from and alongside social class and income.

However, Pincus (1994) points to Antonovsky’s work, which suggests that a strong sense of coherence, a measure of health within, may overcome an unfavourable and unfair social milieu, including “Soweto, unemployment, and hunger”. Frohlich and Potvin (1999) proposed that health promotion should therefore acknowledge not only the role of individual behaviour, but also that of the physical, social and economic contexts that shape both behaviour and health. Dreher (1995) states that in helping people to develop a sense of coherence, confidence or hardiness, clinicians must pay attention to environment, income, lifestyle habits, family dynamics, upbringing and cognitive coping strategies. Sapolsky (1994) claims that a sense of well-being

derives from the personality and perceptual filters of individuals, but also from the society to which they belong, and the capacity of individuals to master or exploit the features of that society. Lenderking and Levine (1995) suggest that one of the major issues that confronted Antonovsky was to establish how social conditions foster the development of a SOC in people. He considered both macrosocial factors and individual socialization processes as equally important. Antonovsky has pointed out how the individual's internal resources are formed by and dependent on the support of the external environment. Orth-Gomer (1994) suggests that a well-functioning social network will provide several kinds of support, the four most distinct types being:

- emotional support usually obtained from close friends or family, providing important tools to enhance self esteem and self-identity;
- appraisal support, often obtained by more peripheral members of the network, such as co-workers, providing help with orienting oneself in life and tools to cope with stresses;
- tangible support, also provided by different kinds of members of the network and varying from simple practical to significant matters; and
- belongingness, or a sense of being part of a group of people with whom one shares values and interests.

Although social support seems to be essential in the establishment of the salutogenic personality, Dreher (1995) suggests that a call for social medicine will never undermine a call to personal responsibility. Yet, the boundaries between personal and social responsibility seems to be not easily defined.

Individual versus social responsibility

As Antonovsky (Dreher, 1995) notes, there is considerable evidence showing that social, economic, and environmental factors and events interact with psychological and physical factors to produce various states of well-being. Moreover, it has been shown that well-being can be affected by intra-individual practices. However, the view that well-being is exclusively the property of the individual, uninfluenced by the

social environment, is not only wrong but also dangerous. It encourages people to assume responsibility for factors outside their control - they blame themselves when they are unsuccessful in controlling their sense of well-being; when others are addressed, they blame them for not adequately marshalling internal resources to overcome adversity and failure. Antonovsky was critical of what he called the well-being movement for ignoring the social context in which individual consciousness is always embedded, and for the view of some that the right mental attitudes can overcome all obstacles (Lenderking & Levine, 1995).

Collectively, these ideas teach us that we must be careful in leading victims of tragedy to believe that they should be able to manage the unmanageable (Sapolsky, 1994). More specifically, the question should be asked: "Which social factors nourish attitudes of optimism or pessimism?" Such a question would lead to a deeper understanding of interventions – both social and behavioural – that reinforce optimism, hope, and self-efficacy. When such questions are not asked and answered, says Antonovsky, the result is the development of treatments that call on people to fix themselves (Dreher, 1995).

Antonovsky points out that a SOC depends not only on one's personality or worldview, but also on "structural sources of salutogenic strengths" (Dreher, 1995). In other words, we can develop a sense of coherence only when we receive coherent messages from our environment, and are granted the opportunity to develop the opportunity to develop the intellectual and emotional skills for interpreting them coherently. The latter point does not ignore an individual's singular ability to develop such skills, but rather recognises that over time our native capacities for coherence and coping can be suppressed, deadened or even destroyed by a brutal environment (Dreher, 1995).

Sapolsky (1994) states that researchers in various disciplines relevant to a sense of well-being have been struggling for a long period of time with discerning the point at which a troubling reality can no longer just be perceived away. Cognitive psychology and its approach to depression is a case in point. The cornerstone of the cognitive

approach is that depression and distortion are intertwined, and that the clearing of distorted perceptions and interpretations will ameliorate depression. What if the depressive's reality is one of unremitting sadness, for example being a refugee or a homeless street person? The attempts of researchers to hold on to the usual approach in dealing with miseries such as these, seem to be particularly unsatisfactory (Sapolsky, 1994).

Stress physiology and the management of stress-related diseases offer another example of the difficulty of dealing with anguish. Dreher (1995) states that these therapies are often successful, because such intentional efforts conducted with the aid of supportive caregivers, are an important aspect of healthy transformations. The other part of the task, the creation of environments in neighbourhoods and workplaces that generate optimism and self-efficacy, remains nearly absent from intervention research. Therapies designed to facilitate coping should clearly take social conditions into account, and they can encourage individuals to shape their own environments (Dreher, 1995).

Dreher (1995) suggests that people who suffer from chronic illness should ideally be in an environment where they are surrounded by caring individuals who convey consistently coherent messages, create an environment of sensible feedback and provide coping options. Such a society does not exist for many people suffering with chronic illness. For instance, some inhabitants of dangerous and depressing environments may have high levels of hardiness, but their ability to maintain these attitudes is determined less by the relative strength or weakness of their characters than by the relative strengths and weaknesses evident in their family systems, neighbourhoods and economic infrastructures. In other words, behavioural interventions may be quite effective in helping people feel more confident and supported, thus improving their health via mind-body interactions, but their efficacy may be limited if the empowerment gained in individual or group sessions is undermined when they go back to their homes and communities.

SPIRITUAL ASPECTS

All the participants in this study had been cared for by the Christian-based Leprosy Mission over a period of time, and some of the participants are deeply committed Christians. The impact of their spiritual experience on coping is an important factor that should therefore not be overlooked.

Ness and Wintrob (1980) established that people who frequently and consistently engaged in religious activities in a well-integrated congregation, reported fewer symptoms of emotional distress. Religion could therefore be perceived as a means of arousing hope and strengthening a person's self-worth. Bergin (1983) conducted a meta-analysis of 24 empirical studies that examined patients' religious values and measures of clinical pathology. He found marginal support for a positive effect of religion. Larson, Pattison, Blazer, Omran and Kaplan (1986) reviewed articles on religion published in major psychiatry journals and concluded that people with mental illness are less religious and engage in fewer religious activities than people who are mentally healthy. Religious beliefs have been found to help people through stressful life events (Krause & Van Tran, 1989), such as cancer and major disasters (Gibbs, 1989). In addition, religious beliefs have been found to provide a meaningful interpretation of existence and to give life a purpose it might not otherwise have.

Kanter (1976) concluded from his clinical work that the Holocaust survivors who were conscious of their ethnic identity and cultural heritage (as factors associated with their religion) tended to be less vulnerable to extreme psychic trauma. Newman (1979) also theorised that religious beliefs are beneficial to survivors, stating that some survivors may have higher self-esteem and stronger feelings of personal control because of a belief in a religion that gives meaning to their experience. Both Kanter (1976) and Newman (1979) have discussed the role of Jewish identity for those trying to survive during the Holocaust. They did not, however, distinguish between escapees and survivors in their studies. The escapees were in a very different situation from the survivors regarding Jewish identity and religion: most escapees had an opportunity to practice Jewish religious rituals and customs after

their escape; those caught in the Holocaust were prevented from engaging in such behaviours for years. Survivors saw themselves and others suffer horrible punishments because they were Jewish. On the other hand, most escapees suffered less and witnessed less suffering. Such different experiences could have altered the Jewish identity and religious convictions of both groups.

It is clear that as the psychological functioning of victims (in whatever context) is under scrutiny, words and actions must be informed by another aspect of healing which the wellness movement too often ignores – spirituality (Gordon, 1994). It is important to remember that the civil rights movement, the “grandparent” of the wellness movement, began in the black churches of the South and was as much a spiritual as a social and political phenomenon. The success of the movement, its ability to affect and change those who were indifferent to or even violently opposed to it, depended on its spiritual core. It was spiritual strength, and the loving generosity that came from it, that enabled people to put their bodies and lives on the line for what they believed in; to do what was right not only for them and those they loved, but even for those who opposed them (Gordon, 1994). It should be remembered that illness represents a spiritual crisis, as well as a physical challenge. Illness enables people to search for something larger than themselves (Gordon, 1994).

CONCLUSION

Sapolsky (1994) comments that even today, in the most horrendous of settings of urban decay, there are those who cope and thrive, and there are often informative ways in which they do so. The question could be asked: What do we do with the lessons in coping that they can teach us? Perhaps two simple and humane rules might be derived from this. Firstly, when trying to help an individual exposed to only moderately severe stressors, it is probably efficacious to inform him or her about the lessons in coping learned from those who have managed far worse. Secondly, not only might the specific guidelines for stress management help, but the knowledge that they work in more severe circumstances should as well. But it is probably

patronizing to preach about coping as privileged outsiders to those in the midst of a truly brutal world. Sapolsky (1994) warns that it would be inappropriate to turn to another victim of a disaster (next to the individual coping miraculously) and blithely offer lessons which, in effect, say “You see, it can be done, buck up now” (p. 4). There is probably little that an outsider can do for people in cruel circumstances other than to validate the tragedy of their situation and to aid them in their means of denial.

The salutogenic perspective however, articulates a goal to which we should aspire. Were it to be achieved, it would mean that housing, education, social services, and medical care were robustly funded and delivered in a safe and clean environment. In the meantime, however, the reality is that (generally speaking) good health is still considered the absence of disease, and resources still flow toward traditional medical services more easily than they do toward housing and social services. Health care reform may eventually offer an opportunity to redefine health and the content of medical care, but this is by no means certain (Gruman, 1994).

In a larger sense, the question remains as to how to maintain fundamental human integrity in the face of the catastrophes of human existence. For posing this question, for formulating an answer and for the enormous intellectual stimulation Antonovsky provided, theorists will forever be grateful to him (Lenderking & Levine, 1995).

CHAPTER FIVE

TREADING ON HOLY GROUND: THE RESEARCH APPROACH

INTRODUCTION

In previous chapters the emotional world of the leprosy sufferer was explored. In order to determine the sense of coherence of leprosy sufferers in Southern Africa, it was imperative to find a suitable research approach which would do justice to this sensitive topic. Qualitative research was decided on as the appropriate research methodology in order to, obtain “in-depth and enriched” information (Patton, 1990; Shields & Twycross, 2003). The views of Glaser and Strauss (1967), who argue that qualitative research can make a valuable and unique contribution by generating a conceptual framework for research that is grounded on information about how people actually “think and feel”, also confirm the appropriateness of such a method for this study. Furthermore, in the past decade there has been an increase in the use of qualitative research in the social sciences in general (Marshall & Rossman, 1999) and in cross-cultural studies (Degner & Woodgate, 2003). At a most basic level, much of what we know about human nature is based on data derived from the contributions of qualitative research (Damico & Simmons-Mackie, 2003; Fossey, Harvey, McDermott & Davidson, 2002).

Although qualitative research lends itself to develop knowledge in complex areas of health care and support services (Fossey, *et al.*, 2002), the application of qualitative research methodology has been less progressive in these fields (Meadows, 2003). A possible reason for this is that qualitative research is often viewed as being unscientific and lacking rigour, and that its findings are not generalisable (Mays & Pope, 1995). However, in a climate of ever-increasing complexity in the provision of health care and related support services, traditional quantitative methods are not always the most appropriate for dealing with questions that investigators are now

asking (Meadows, 2003). It is implied that different research purposes require the use of different research methods, separately or in combination with one another (Sogunro, 2002).

Apart from the discussion of key issues in qualitative research, starting with a description of qualitative research and the collection of qualitative data, the sufficiency of qualitative research with reference to the establishment of the sense of coherence in leprosy patients in South Africa, will be suggested. Furthermore, an overview on ensuring rigour in qualitative research and the analysis of qualitative data will be introduced.

Firstly, it is essential to give a lucid definition of qualitative research, as well as a distinction between this type of research and quantitative research.

DEFINING QUALITATIVE RESEARCH

Qualitative research is a broad term that constitutes a variety of approaches to interpretive research. Although novice researchers may tend to group these approaches together and refer to them by any of their names (for example case study, ethnography), those who use these approaches are often quite clear about the unique qualities of each (Leedy, 1997). Although the approaches are not synonymous, as variations of qualitative inquiry, they naturally share a number of similarities. Yet, each approach can be distinguished from others by its unique focus, research methods, and analysis, as well as specific ways of communicating results (Leedy, 1997). Qualitative research can, for example, be historical, sociological, political and educational. Although qualitative studies in social science disciplines have increased in recent years, it is a misconception to consider qualitative research as 'new' or 'modern'. In fact, many researchers believe that all inquiry commenced as qualitative in nature. Centuries ago, when reading and writing were not yet developed, people communicated their observations and experiences through detailed oral descriptions that were later combined into series of stories. These stories helped others understand what was previously observed or experienced and provided a base for extending knowledge of phenomena. Today, when insufficient

information exists on a topic, or when a relevant theory base is inadequate or incomplete, a qualitative study can help define what is important, that is, what needs to be studied (Leedy, 1997).

Research methodologies can be broadly categorised into either qualitative or quantitative methods (Meadows, 2003; Shields & Twycross, 2003). Quantitative research focuses on the use of standardised methods (such as questionnaires) to collect information which is then transformed into numbers to enable some statistical analysis in order to explain, predict and/or control phenomena of interest (Marshall & Rossman, 1999; Meadows, 2003; Shields & Twycross, 2003). On the other hand, the aim of qualitative research is to help in the understanding of social phenomena in a natural rather than experimental setting with emphasis on the meanings, experiences and views of participants, rather than providing quantified answers to a research question (Airasian & Gay, 2000; Mays & Pope, 1995; Shields & Twycross, 2003). Data obtained from qualitative research are usually in the form of words rather than quantified numbers and these words are based on observation, interviews or documents (Fossey, *et al.*, 2002; Meadows, 2003; Punch, 1998; Shields & Twycross, 2003). It is thus clear that the focus of qualitative research is to determine “why?” rather than “how many?” Miles and Huberman (1994) have identified a number of recurring features of qualitative research. These include:

- The researcher aims at gaining a holistic overview of the context under study;
- Data are captured on the perceptions of local ‘actors’ (individuals) from the inside; and
- Relatively little standardised instrumentation is used.

Qualitative research is also often described as essentially inductive in its approach, for example, it is data-driven, with conclusions being drawn directly from the data (Dunnagan, Peterson & Wilson, 1997; Fossey, *et al.*, 2002). This is in contrast to the deductive approach commonly used in quantitative research, whereby variables are controlled and hypotheses are formulated and tested in the data specifically collected for the purpose (Damico & Simmons-Mackie, 2003; Dunnagan *et al.*, 1997; Marshall & Rossman, 1999). Another area, in which qualitative research can be applied, is

the study of complex behaviours and attitudes from the perspective of the patient and/or the professional. This area of study is not always open to quantitative research methodology (Fossey *et al.*, 2002). Research utilised in this area is often referred to as “stand alone qualitative research”, which is increasingly evident in studies of health service organisation and policy (Mays & Pope, 1995).

While it seems as if there are some clear differences between quantitative and qualitative research methodologies, Mays and Pope (1995) have emphasised the importance of avoiding a rigid distinction between the two research traditions. Rather, they view both research traditions as complementary. For example, qualitative work can be the preliminary phase to a quantitative study where there is an absence of prior research or theory (Marshall & Rossman, 1999). At its simplest, this qualitative leg can be to identify the terms or words for use in the subsequent survey questionnaire, or to provide a description and understanding of a behaviour or situation (Damico & Simmons-Mackie, 2003; Fossey *et al.*, 2002). In some cases, the two approaches are compatible and can be combined, for example, qualitative results can be used to help validate quantitative results (Dunnagan, Peterson & Wilson, 1997; Punch, 1998). The use of a combination of both quantitative and qualitative methods results in a stronger validity of outcomes (Sogunro, 2002). Conducting qualitative descriptive research is a prerequisite for all types of experimental research. Unless the important dimensions and concepts of a field have been identified, explicit cause-and-effect relationships cannot be tested in quasi-experiments. The medical field, as an example, has made extensive use of qualitative methods when unique or incomprehensible cases are first observed (Leedy, 1997). Even in empirical studies, the dimensions require subjective or experimenter labelling. Alternatively, the use of qualitative techniques can supplement the findings of a quantitative study, for example, by exploring ethnic differences in the experience of psychiatric illness, which underlie the findings of a survey (O'Connor & Nazroo, 2002). Similarly, qualitative methods can be used as part of a process of triangulation (Fossey *et al.*, 2002), in which different methods of data gathering are used to examine a single phenomenon in an attempt to increase reliability (Marshall & Rossman, 1999).

To summarise, Meadows (2003) has described the important purposes of qualitative research as:

- Description
These are usually cases where little is known about a group of people or social phenomena;
- Hypothesis Generation
This generally occurs when no explicit hypothesis exists and where the collection of in-depth information enables the formulation of hypotheses, which could be evaluated more formally in subsequent research; and
- Theory development
Here qualitative data are analysed with the view of developing an integrated scheme to explain the observed phenomena.

According to Mouton (2001), qualitative research enables the researcher to gain a deep understanding of the experiences, perceptions and beliefs of the participants. A qualitative research approach will therefore be followed in this study as it fits with the aim of the research, namely to obtain an in-depth and rich understanding of the experience of leprosy through listening to the voices of the participants. A quantitative method is however included in the initial screening of participants, as participants who obtained high scores on Antonovsky's Life History Questionnaire were included in the final sample.

COLLECTING THE INFORMATION

Qualitative research meets different objectives than those met by quantitative research and as a consequence provides a very different type of information (Meadows, 2003). The information provided by the latter is often unstructured and more often than not, consists of verbatim transcripts from discussions with the participants, field notes and other written documents (Fossey, *et al.*, 2002). The principal methods of obtaining qualitative data are the research interview and/or group discussion (also known as focus groups), analysing written documents and

direct observation (Dunnagan *et al.*, 1997; Fossey *et al.*, 2002; Marshall & Rossman, 1999). While detailed information can be obtained from group discussions, it is likely that the detail will not compare well with the in-depth information obtained from separate in-depth interviews. Consequently, group discussions are, according to Meadows (2003), likely to be less suitable than in-depth interviews when the objective is to develop hypotheses and identify personal motivations.

Fossey *et al.* (2002) distinguish three main types of interviews, namely structured interviews, semi-structured interviews and in-depth interviews. Structured interviews ask standardised questions with predetermined responses, for example, "How would you rate your ability to cope over the past seven days? Excellent, good, fair or poor?" Semi-structured interviews, on the other hand, are conducted using a loose structure of open-ended questions which define the area to explore and which the participant can answer in his or her own words, for example, "What would you describe as good coping?" Lastly, in-depth interviews (also known as unstructured interviews) are the least structured type of interviews, and are the main method used in qualitative research for obtaining information. A detailed description of in-depth interviews follows.

Qualitative interviewing

In contrast to surveys where questionnaires are rigidly structured, less structured, in-depth interviews are found to be more appropriate with regard to field research (Babbie, 2001). Such in-depth interviews should be flexible, interactive, and responsive (Meadows, 2003). The questions should be worded in such a way that participants are encouraged to provide a detailed response in their own words (Degner & Woodgate, 2003). Good questions in qualitative research seem to be open-ended, neutral and clear to the interviewee and they can be based on behaviour or experience, opinion or value, feeling, knowledge and sensory experience (Meadows, 2003). The distinction between questionnaires and less structured interviews is described as follows, "qualitative interviewing design is

flexible, iterative, and continuous, rather than prepared in advance and locked in stone” (Rubin & Riene, 1995, p 43).

However, the process of undertaking an in-depth interview can and should preferably be facilitated through the use of a topic guide (Fossey *et al.*, 2002). This is a list of topics or themes to be explored during the interview. How these topics and themes are phrased as questions is normally at the judgement of the interviewer. However, care should be taken when formulating the questions to ensure that they are comprehensible to the participants. The topic guide is just a guideline, and should not be used in a way that restricts the flexibility and interactive nature of the interview or responsiveness of the participants’ answers (Meadows, 2003).

During the interview, the interviewer has a general plan of inquiry, but not a specific set of questions with particular wording and in a particular order (Babbie, 2001). The interview should be conducted in a way that enables participants to spontaneously emerge with themes that might not have been previously considered relevant by the researcher (Degner & Woodgate, 2003; Meadows, 2003). According to Fossey *et al.* (2002) and Meadows (2003), encouraging people to speak freely about themselves is an essential requirement of qualitative research, which can be achieved by personalising the discussion. Babbie (2001) states that a qualitative interview is essentially a conversation in which the interviewer creates a general direction for the conversation and pursues specific topics raised by the participant. Marshall and Rossman (1999) claim that, unlike a survey, a qualitative interview leads to emphasis being placed on the continuous interaction between an interviewer and a participant. Rubin & Riene (1995) elaborate by stating that each time the basic process of gathering information is repeated, analysed, and tested, the researcher comes closer to a clear and convincing model of the phenomenon that is studied.

The recurrent nature of qualitative interviewing implies that the questioning is redesigned throughout the project. Although researchers may set out to conduct interviews with a relatively clear idea of what they want to ask, one of the special strengths of field research is its flexibility. In particular, the answers evoked by initial

questions, should shape consequent ones. Babbie (2001) maintains that the researcher should have the ability to get answers in more depth without biasing later answers. Rubin and Riene (1995) offer ways to control a guided conversation. According to them, it is easier to maintain a conversational flow from one topic to another if the numbers of main topics are limited. Transitions between topics should be smooth and logical. The more abrupt the transition, the more it appears as if the interviewer has an agenda that he or she wants to get through, rather than wanting to hear what the interviewee has to say. Because field research interviewing is very much like normal conversation, researchers must remember that they are, however, not having normal conversations. In normal conversations, each of the participants want to come across as an interesting, worthwhile person (Babbie, 2001), while, as an interviewer, the need to appear interesting is counterproductive. Essentially, the interviewer needs to make the other person seem interesting by being interested. He should, therefore, be listening more than talking.

Both verbal and non-verbal cues can help in encouraging the participant to feel that he or she is the focus of attention and to talk openly. The use of a simple 'mmm' or 'uh-huh' shows understanding and interest, which can encourage discussion. Participants can also be asked probing questions ("probes") to motivate them to provide more detail (Meadows, 2003). A distinction should be made between prompting and probing. Prompting implies the "leading" of a participant to say something not in his or her own words. This is very different from probing; which means reflecting the participant's comment back to him. Another technique is to repeat the expression made by the participant. An example of this is "You said you found it very difficult to cope when...?", which can be followed by an expectant pause to encourage a response (Meadows, 2003). Non-verbal cues to encourage openness from the participant include taking an open and relaxed posture, making good eye contact and nodding of the head to show interest or understanding. The participant's views should be considered as valuable and useful (Marshall & Rossman, 1999).

Carrying out qualitative interviews requires a considerable amount of skill, and to maintain control of the interview is difficult. It is for example important to choose the appropriate degree of directiveness to maintain that control. Some of the common pitfalls in interviewing include: jumping from one subject to another, giving interviewees advice, offering one's own perspective (so possibly biasing the interview), and asking embarrassing or awkward questions (Meadows, 2003). According to Rossman and Rallis (1998), the researcher should carefully scrutinise the "complex interplay of our own personal biography, power and status, interactions with participants and written word" (p 67). The length of an in-depth interview is dependent on a number of factors, which include the resources and time available to carry out the interviews, the depth of enquiry and age of the target group. Normally, interview fatigue sets in for both interviewer and interviewee if interviews are over 90 minutes to two hours (Meadows, 2003). Information gathered through in-depth interviews is often supplemented by information accumulated via observations.

Recording observations

One of the greatest advantages of the field research method is the presence of an observing, thinking researcher on the scene of the action (Babbie, 2001; Taylor, 2002). Even tape recorders and cameras cannot capture all the relevant aspects of social processes. Consequently, in both direct observation and interviewing, it is essential to make full and accurate field notes (verbatim transcriptions of the participants' own words) of what goes on (Fossey, *et al.*, 2002). When immediate note taking is not feasible, notes should be taken as soon as possible afterwards. In notes, empirical observations, as well as interpretations of them, have to be included. In other words, the researcher records what he 'knows' and 'thinks' has happened.

Like effective field research, however, good note taking requires careful and deliberate attention and involves specific skills (Babbie, 2001). Firstly, the researcher should not rely too much on his or her memory. Secondly, it is usually a good idea to take notes in stages. In the first stage, the researcher needs to take sketchy notes (words and phrases) in order to keep abreast of what is happening.

Then later, notes should be written in more detail. If it is done soon after the events the researcher observed, the sketchy notes should allow him to recall most of the details. Babbie (2001) notes that the longer the delay, the less likely the researcher will be able to recall things accurately and fully. This method sounds logical, but it takes self-discipline to put it into practice. Careful observation and note taking can be a tiring process, especially if it involves excitement or tension and if it extends over a long period of time. Thirdly, researchers sometimes wonder how much they should record. It is really worth the effort to write out all the details that can be recalled right after the observation had been made.

Although researchers are inevitably selective in what they observe (Bennett, 2002), generally, in field research the researcher cannot be absolutely sure of what is important and what is unimportant until he or she has had a chance to review and analyse a great volume of information. The researcher should therefore even record things that do not seem important at the outset. They may turn out to be significant after all (Babbie, 2001). Even though most of a researcher's notes may not be reflected in the final report on the project, detailed note taking should be considered as an inevitable phase in the research process. Observing and recording are professional skills and like all worthwhile skills, they improve with practice.

Interviews and observations were the principal methods utilised in the present study to obtain in-depth information and to develop a complex understanding of the phenomena being studied. The quality of data is improved by gathering data from multiple sources in multiple ways to illuminate different facets of situations and experiences. This practice is referred to as triangulation and contributes to portraying situations and experiences in their complexity (Fossey, *et al.*, 2002).

In theory, qualitative research methods appear to be the ideal way of gathering information. However, as with all research methods, qualitative research methods have also proved to have pitfalls. A discussion on the strengths and weaknesses of qualitative research follows.

STRENGTHS AND WEAKNESSES OF QUALITATIVE FIELD RESEARCH

All research methods seem to possess inherent strengths, as well as weaknesses. For example, there is research that suggests that the intended meaning of a survey question is not always universally shared among all participants (Meadows, 2003). Similarly, a researcher needs to acknowledge the fact that his or her presence can influence the observed behaviour. Quantitative research, unlike qualitative research, is able to deliver statistical models and report statistically significant findings. These may or may not be fully justified, but do seem to attribute some truth-value to the findings regarding their reliability and validity. However, the fruitfulness of qualitative research seems to depend to a large extent on the skills of the researcher, the relevance of the questions asked and the methods used to answer them (Meadows, 2003).

According to Babbie (2001), field research is especially effective for studying subtle nuances in attitudes and behaviours and for examining social processes over time. Babbie (2001) states that as such, the chief strength of the qualitative field research method lies in the depth of understanding it permits. Whereas other research methods may be challenged as “superficial”, this charge is seldom lodged against qualitative field research.

Flexibility is another advantage of field research. The field research design can be modified at any time. Moreover, the researcher is always prepared to engage in field research, whenever the occasion should arise, whereas he or she could not as easily initiate a survey or an experiment (Babbie, 2001). Field research can be relatively inexpensive as well. Other social scientific research methods may require expensive equipment or an expensive research staff, but typical field research can be undertaken by one researcher. This is not to say that field research is never expensive. The nature of the research project, for example, may require a large number of trained observers. Expensive recording equipment may also be needed (Babbie, 2001).

Field research may have other weaknesses as well. Firstly, being qualitative rather than quantitative, it is not an appropriate means for statistical descriptions of a large population (Babbie, 2001). When the strengths and weaknesses of a research method are highlighted, the question of the validity and reliability of the method is normally a burning issue. Validity and reliability are both qualities of measurements. Validity concerns whether measurements actually measure what they are supposed to measure, rather than something else (Fossey, *et al.*, 2002). Reliability, on the other hand, is a matter of dependability: If the researcher makes the same measurement again and again, would he get the same result? Extensive research has been performed on the validity and reliability of qualitative research. For the purpose of this study, a short discussion on the validity and reliability of qualitative research follows.

Validity

The strength of a qualitative study that aims to explore a problem, or describe a setting or a process, will rest with its validity (Marshall & Rossman, 1999). Field research seems to provide measures with greater validity than do survey and experimental measurements, which are often criticised as being superficial and invalid (Babbie, 2001). 'Being there' is a powerful technique for gaining insight into the nature of human affairs in all their complexity (Marshall & Rossman, 1999). The kinds of comprehensive measurements available to the field researcher tap a depth of meaning in concepts, such as common fears and coping skills of leprosy sufferers that are generally unavailable to surveys and experiments. Instead of specifying concepts, field researchers commonly give detailed illustrations (Babbie, 2001).

Reliability

Reliability is concerned with the consistency of the measuring instrument (Patton, 1990). Field research has been perceived by some researchers as having a potential problem with reliability (Kirkeveld & Lomborg, 2003). Although in-depth, field research measurements are also often very personal and may lead to a situation where the researcher 'projects' his or her own issues onto the research process (Marshall & Rossman, 1999). Researchers who use qualitative techniques are conscious of this issue and take plans to address it. It was therefore imperative that the researcher had to sort out his own biases and viewpoints. In short, it is prudent to be wary of purely descriptive measurements in field research, whether one's own, or someone else's (Babbie, 2001). As Fossey, *et al.*, (2002) stated, central to qualitative research is the question whether participants' perspectives have been authentically represented in the research process, and whether the findings are coherent in the sense that they "fit" the data and social context from which they were derived. Field research has proven to be a potentially powerful tool for social scientists, one that may provide a useful balance to the strengths and weaknesses of experiments and surveys. A more detailed description of the qualitative approach in this study follows.

THE QUALITATIVE APPROACH IN THE PRESENT STUDY

Participants and procedures

The central criterion for selecting participants was their "assumed" ability to cope with leprosy. Five members of the Leprosy Mission who have contact with leprosy patients (from different provinces) were each asked to administer the Life History of thirty leprosy patients who (in their perception) had an assumed ability to cope. These members were mainly tertiary trained nursing and social work personnel appointed to address the biopsychosocial needs of leprosy patients. The Life History Questionnaire was verbally administered by these members from the Leprosy Mission. The questionnaire was

administered in English and not translated into any other language. The interviewers made sure that the participants understood the questions. The results on these questionnaires were compared and nine respondents from Kwa-Zulu Natal and one respondent from Gauteng were identified as respondents who achieved high scores (compared to other respondents) on the questionnaire and therefore served as suitable participants for the main study. The two members of the involved provinces were requested to arrange interviews with the respondents.

Main study

The participants were five black males and five black females suffering from leprosy. Only one of the participants (a female) came from the Gauteng area, while the rest were from Kwazulu Natal. The purpose of the study was explained to the participants. They were told that participation was entirely voluntary, and that they were free to withhold answers to any questions that might arise during the course of the interview. Anonymity was assured. Given that the study was inductive and sought to identify whether sense of coherence (SOC) constructs played a role in the way leprosy sufferers coped with the disease, in-depth interviews and non-participant observations were considered to be the most effective approach to obtain the data. The use of interviews and observations provided diverse perspectives in seeking answers to the research question and, in so doing, helped strengthen the rigour of the study. The decision to use interviews was thus influenced by the nature of the research question and the chosen methodology. Although these factors were important considerations in deciding on the methods of study, at the heart of the activity was a desire to understand the experience of leprosy sufferers and the perceptions they had about the experience (Seidman, 1991).

One of the aims of the study was therefore to understand the social reality of the interviewees (Annels, 1997) and, as described by Marshall and Rossman (1999), “examine and analyse the subjective experience of individuals and their constructions of the social world” (p 120). It is only when in-depth interviews are used that these psychosocial processes can be identified (Morse, 2002). The study focussed on

individuals' lived experience with leprosy and as Marshall and Rossman (1999) advise for this kind of study, in-depth interviews were conducted. In the main study, semi-structured interviews were conducted with the participants after they had given a short presentation of their life history.

Not only was the interview schedule (Annexure 2) utilised as a guide, but the researcher also used psychotherapeutic conversational skills in order to generate in-depth information. The interviews included structured (closed) questions, but were mainly performed as thematically structured (open) interviews conducted in a conversational form intended to cover certain themes. Taken together, these themes were aimed at providing broad information concerning everyday life. The questions asked were built around wide interview themes exploring SOC constructs. These were conversation type themes, which moved from general issues to specific themes allowing informants to answer on their own terms. Preceding questions in the interviews were used to deepen and broaden subsequent themes.

According to Biley and Smith (1997), questions must be flexible, open-ended and broad enough to enable a thorough investigation to be carried out on facets of a phenomenon, while providing adequate focus for the researcher. Care was therefore taken to avoid imposing too much structure on the interview, to prevent affecting the quality of the data (Schreiber, 2001). In addition, as Marshall and Rossman (1999) suggest, the researcher engaged in some preliminary self-reflection to uncover personal subjectivities and to ensure theoretical sensitivity (Glaser, 1978). In this study it was therefore imperative that the researcher had to sort out his own viewpoints. The researcher did not allow his own views to direct the participants as it was their stories that needed to be heard. The interviews gave the researcher the opportunity to ask a range of in-depth questions, allowing the informants to describe their experiences about what enabled them to cope with the bio-psychosocial implications of the disease in their own narrative (Patton, 1990).

The fact that most of the participants in this study were illiterate played an important role in the selection of this research method. If, for example, a questionnaire had been administered, the researcher would not have had the opportunity to clarify some of the

answers given by the participants. Taking into consideration that the researcher experienced some of the interviewees as struggling with abstract thinking, the interviews at times did not 'flow' ideally, and the researcher had to refrain from being directive. Mitchell, Peil and Rimmer (1982) are of the opinion that where illiterate participants are involved, the interviews should not be too long. The interviews conducted by the researcher were therefore restricted to approximately 90 minutes. The rules formulated by Lonner and Berry (1986) to reduce the problems of translating to a target language, were applied. Questions were formulated in the subject's own idiom and therefore an interpreter had to be used in some instances.

According to Gilner (1994), credibility of data is established by verifying patterns of agreement based on more than one data source. In addition, non-participatory observation took place without predetermined categories. Comprehensive field notes were taken. Amongst others, the following aspects were taken note of:

- the non-verbal behaviour of the participants;
- affect shown in addition to the participants' words; and
- the interaction between the participants and personnel of the Leprosy Mission

Apart from conversations with personnel of the Leprosy Mission at head office in Johannesburg about the current biopsychosocial care of leprosy sufferers, the researcher spent a week doing research at the Prince Mshiyeni Hospital in Umlazi (Durban). This opportunity gave him a chance to observe how the Leprosy Mission was instrumental in the care of leprosy sufferers. Discussions with personnel of this office also provided rich insights into the psychosocial functioning of leprosy sufferers.

Furthermore, observations enabled the researcher to gain an "insider's" view of the field study (Porter, 1996), to verify dialogue from the interviews and to observe whether there was a discrepancy between what the informants said (in the interviews) and what actually took place in practice. Triangulation of method was achieved by using these two different types of data collection: interviews and observations. This mixed method

approach to data collection, was thus chosen because it was felt that it would produce richer data than a single approach. The decision was also influenced by conflicting literature about the rigour of using a single approach (Benoliel 1996; Charmaz 2000; Glaser 1992; Morse 2002). Observations also enabled identification of questions for subsequent discussion in the interviews.

The fact that personnel of the Leprosy Mission exchanged information about participants, provided triangulation of sources. Triangulation of sites occurred when data were obtained from a participant living in a rural area in Gauteng and participants in Kwazulu-Natal living in rural and urban areas. In addition, an approximately equal gender distribution was sought in the sample. Empirical data from the interviews were continuously compared and theoretically analysed in accordance with the requirements of grounded theory (which will be discussed later).

Practical considerations complicated this study. The researcher travelled from his hometown in the Free State to other provinces to conduct this study. Some of the participants also had to travel far distances, using public transport. They commuted from their homes in not-easily accessible rural places to Prince Mshiyeni Hospital, where some of the interviews were conducted. As some of the interviewees were needy, the researcher felt ethically obliged to offer financial assistance to cover travel and lodging expenses. Where practically possible the researcher conducted the interviews in the privacy of the homes of some of the interviewees. It was not possible to conduct interviews more than once with the same participant, excluding the two interviews with the participant in Gauteng.

Two of the participants were English, one was Tswana and the rest Zulu speaking. Since the researcher was unable to conduct interviews in Tswana and Zulu, an employee of the Leprosy Mission served as an interpreter. Apart from English, he also has command of four black languages and was therefore able to communicate with all the participants. He was friendly, patient and empathetic towards leprosy patients. The participants gave honest answers more readily after a relationship of trust had been established with the interviewer. In a previous study conducted by Scott (1992), it was clear that some of the participants had a fear of being identified by the community as leprosy sufferers. Ethical issues were therefore a burning issue and a detailed discussion of this complex aspect therefore follows.

Ethical issues

The management of the Leprosy Mission was given the assurance that ethical issues were considered of the utmost importance. In accordance with guidelines set by Marshall and Rossmann (1999), there was full transparency about the purpose of the study, and assurance was given to the participants that their anonymity would not be jeopardised. More specifically, the following measures were put in place:

- It was made clear to participants that their life stories would be published. Some of the participants requested a copy of parts of the published thesis and indicated their satisfaction with the way in which their stories were told and interpreted.
- Participants were given the assurance that only pseudo names would be used.
- No participants were photographed. Photos were taken at one of the respondent's house (Peter). He was given the assurance that only the steps at his house would be photographed.
- A photocopy from one of the respondent's medical file (Jalo) was included. He was given the assurance that his actual name would not appear on the photocopy.

Research location

The research was conducted in three locations. Participants were interviewed at the offices of Prince Mshiyeni Hospital in Durban (See Image 5.1 and Image 5.2), Sonop Old Age Home in Gauteng and in their homes. The interviews were conducted privately, with only the researcher and the interviewee present. If an interviewee was unable to understand or speak English, the interpreter took part in the interview. Language was a constraint and it was very important to ensure that the interviewee and the interpreter clearly understood what the researcher was saying or asking.

Research by Peil *et al.* (1982) indicated that rapport was easier established where participants had been contacted previously. A nursing sister at The Leprosy Mission at Prince Mshiyeni Hospital, who knew the participants personally, arranged all



Image 5.1
Entrance to Prince Mshiyeni Hospital Nursing Campus, Durban



Image 5.2
Main gate to Prince Mshiyeni Hospital



Image 5.3
A Leprosy Mission employee at the Prince Mshiyeni
Hospital prepares ulcer ointment

Kwazulu Natal interviews on behalf of the researcher. The fact that this sister – as part of The Leprosy Mission - attends to the social and economic welfare of the patients, prepared the way for positive rapport with the interviewees.

QUALITATIVE RESEARCH DESIGNS

Qualitative research has grown out of diverse disciplines (anthropology, sociology, psychology) that are marked by distinctive interests, theories, and research methods (Meadows, 2003). Four of the most common qualitative designs are: case study, ethnography, phenomenology and grounded theory (Meadows, 2003). Each of these approaches is considered to be primarily interactive field research. In this study the qualitative grounded theory approach is used to analyse the participants' SOC as revealed through personal narratives. In addition to a description of the origin of grounded theory, the theory will be defined and an account of sampling and coding, categorising and analysis of data will be given.

GROUNDING THEORY

Historical background

Grounded theory was originally developed by two collaborating sociologists at the University of California (San Francisco), Barney Glaser and Anselm Strauss, in an attempt to comprehend their research in medical sociology (Glaser & Strauss, 1967; Strauss & Corbin, 1990; Strauss & Corbin, 1998). The first major presentation of this method is described in Glaser and Strauss's book, *The discovery of the grounded theory*

(1967). Although the men came from a different philosophical and research tradition, their respective contributions were equally important (Cowley & Heath, 2004). Since then, their contributions have evolved as a method, with the co-founders taking it in slightly different directions.

The grounded theory approach was developed in response to the prevalent view of quantitative research being the only model of social science research (Charmaz, 2000). It is considered by some to be the most comprehensive qualitative research methodology available (Annels, 1997). The underlying assumption of grounded theory is that people make sense of and order their social world even though, to an outsider, their world may appear irrational. Individuals sharing common circumstances (for example, clients with mental illness) experience common perceptions, thoughts, and behaviours, which are the core of grounded theory (Strauss & Corbin, 1998).

Researchers using this approach base their work on the belief that each group experience a common social psychological problem that is not always articulated (Hutchinson, 1993). The initial aim of the researcher is to identify this problem (Schreiber, 2001). In previous research performed by the researcher, the common psychosocial problems that leprosy patients shared were explored. This research is an attempt to establish whether SOC strategies are applied in order to cope with these psychological stressors. A definition of grounded theory and a discussion of related characteristics follow.

Grounded theory and related characteristics

Grounded theory can be defined as an approach that attempts to combine a naturalist approach with a positivist concern for a “systematic set of procedures” in doing qualitative research (Babbie, 2001). According to Strauss and Corbin (1994), grounded theory is a “general (research) methodology, a way of thinking about and conceptualising data” (p 275).

Although Glaser and Strauss (1967) wanted to close 'the embarrassing gap between theory and empirical research' (p vii), grounded theory is not perceived to be discipline-bound. Some qualitative researchers attempt to establish theories on a purely inductive basis. Instead, this approach begins with observations rather than hypotheses and seeks to discover patterns and develop theories from ground up. Although new theories may emerge, without having any prior preconceptions, some research may build and elaborate on earlier grounded theories (Babbie, 2001; Abu-Saad, Goldsteen, Proot, Spreeuwenberg, Ter Meulen & Widdershoven, 2004). The researcher is thus guided by initial concepts, but shifts them as he collects and analyses the data (Marshall & Rossman, 1999).

These immersion strategies do not prefigure categories and rely heavily on the researcher's intuitive and interpretive capacities (Marshall & Rossman, 1999). Theory derived from data is more likely to resemble the 'reality' than is theory derived by putting together a series of concepts based on experience or solely through speculation. Grounded theories, because they are drawn from data, are likely to offer insight, enhance understanding, and provide a meaningful guide to action (McCallin, 2003; Strauss & Corbin, 1990).

The presentation of findings differs, for example, conceptual models and theories are not synonymous. A conceptual model is general and abstract and provides a broad perspective on specific paradigms. Theories (grand or middle-range) are more concrete, specific and limited in range than conceptual models (Fawcett, 1995). Two types of theories can be developed using grounded theory, namely formal or substantive theories. **Formal theories** are more general than substantive theories and deal with a conceptual area of enquiry, such as illness experience, professionalism and power relations in clinical practice. **Substantive theories**, which are the most common type of theories that are derived from grounded theory (Morse, 2002), concentrate on specific social processes and are developed for narrower empirical areas of study, such as

therapeutic touch and care for the dying. This study can be described as formal and explorative.

Other characteristics of grounded theory are the processes of induction, deduction and verification. Induction requires the researcher to use a ground-up (from practice to theory) approach, to enter the field with no preconceived hypotheses from literature or elsewhere, and to be open-minded and accommodating, so that the theory emerges from the data (Carpenter, 1995; Glaser & Strauss, 1967; Strauss & Corbin, 1990; Strauss & Corbin, 1998). Only after initial data collection can provisional hypotheses be formulated. Empirical verification of the hypotheses is undertaken through further data collection (Benton, 1993; Charmaz, 1990; Holloway & Wheeler, 1996; Strauss & Corbin, 1990; Strauss & Corbin, 1998). The theory can then be tested, allowing predictions to be developed deductively from general principles (Carpenter, 1995).

It is important that the theory is grounded in the data and not predetermined by any theoretical perspective. That is to say, the data have primacy. The researcher must be immersed in the data; the culture and setting for the study. Immersion in the data will assist the researcher to use the conceptual density or “thick description” of categories, enabling a thorough and clear portrayal of the situation (Denzin, 1989). To obtain conceptual density, grounded theory methodology requires an “emic” or insider approach when collecting and analysing the data. This entails having empathetic understanding of the insider’s point of view, exploring and uncovering the meanings given to ideas, feelings, experiences, and perceptions, rather than imposing an “etic” or researcher or outsider perspective (Boyle, 1994; Stern, 1994). The researcher then takes an ‘etic’ perspective to interpret the meanings of participants and provides an explanation for events and actions, enabling the systematic development of the phenomenon (Boyle, 1994).

Because of its universality, grounded theory is easily adapted to in-depth studies of diverse phenomena (Woods, 2003). A range of topics that have been the focus of grounded theory research are listed by Strauss and Corbin (1994). These include

remarriage after divorce, the work of scientists, homecoming, experiences with chronic illnesses, and spousal abuse. Grounded theory has the following seven key

suggests that other researchers differentiate theoretical sampling from purposeful sampling. According to Cutcliff (2000), purposeful sampling involves a conscious decision to sample a specific area because of a preconceived initial set of dimensions, whereas theoretical sampling is driven by the emerging theory.

Strauss and Corbin (1998) make no such distinction in terminology, but do describe two phases of sampling that occur sequentially in the research process. According to Strauss and Corbin (1998), the researcher makes some initial sampling decisions regarding the group to be studied, the types of data to be used, the length of the study, and the number of observations and/or interviews. Later, the researcher may alter these decisions, according to the evolving theory. In grounded theory the researcher continues sampling until nothing new is being said about the concepts under exploration, and the collected data have reached saturation point (Cutcliff, 2000; Fossey, *et al.*, 2002; Glaser & Strauss, 1967; Henwood & Pidgeon, 1996). According to Strauss and Corbin (1998), saturation is always a matter of degree, stating that there is always a potential for the “new” to emerge (Strauss & Corbin, 1998). Saturation is considered the point in research where collecting additional data seems counterproductive in that the newly uncovered does not add more explanation, or the researcher runs out of time, money or both (Strauss & Corbin, 1998).

Theoretical sampling in the present study

In the present study, purposeful sampling (Patton 1990) was initially used. The central criterion for selecting participants was their “assumed” ability to cope with leprosy. The Life History Questionnaire (Annexure 1) was conducted on possible high SOC leprosy sufferers identified by The Leprosy Mission personnel. Participants who were included in the main study, proved to have a high SOC, according to their scores on the Questionnaire. After analysing the early data from the first couple of participants, further sampling was based on the categories and the developing theory.

Constant comparative analysis

An important benefit of grounded theory is its flexibility and open-endedness (Charmaz, 1990). Using this method, all codes are compared repeatedly within and between one another until the basic properties of a category or construct are defined (Bailey, 1997; Henwood & Pidgeon, 1996; Degner & Woodgate, 2003). Constant comparative analysis is the principal approach to data analysis in the development of grounded theory (Charmaz, 2000). Part of this is to evaluate the data for their usefulness and centrality (Marshall and Rossman, 1999). According to Glaser and Strauss (1967), there are four stages in the constant comparative method:

- comparing incidents applicable to each category;
- integrating categories and their properties;
- delimiting the theory; and
- writing the theory.

The process of constant comparison continues until a theory with sufficient detail and abstraction is generated. According to Boeije (2002), literature does not make clear how one should “go about” constant comparison. Morse and Field (1998) state that each piece of data must be compared with every other piece of relevant data, but Boeije (2002) believes that there is more to the process than just comparing everything that crosses the researcher’s path.

Data preparation and analysis in the present study

Interviews were tape-recorded and field notes (consisting of the interviewees’ own statements), associations and narratives, along with the interviewer’s reflections, were dictated onto a tape recorder at the earliest opportunity. Complete interviews and tape-recorded and handwritten field notes and memos were transcribed onto a word processor following each episode of fieldwork. The use of diagrams and memos were

vital in the analytical process. Diagrams visually represent the conceptual relationship that develops among categories (Strauss & Corbin, 1998). They assist the researcher to identify the consistency of these relationships.

Memos are notes that the researcher makes throughout the research in order to record and explicate the theory as it is developed (Stern, 1994; Smith, 1997). They are essential for capturing the idea, and for abstraction and theory development, which continues throughout the research (Charmaz, 2000; Henwood & Pidgeon, 1996). Memos reflect the researcher's initial dialogue with the data at a point in time. Memoing is both inductive and deductive. It is inductive during the process of conceptualising the data, and deductive when the researcher assesses how the conceptual labels, categories and subcategories link together (Hutchinson, 1993; Marshall & Rossman, 1999). Memo writing provides the researcher with a way of analysing and questioning "taken for granted aspects" of the research process and preconceptions about the data (Charmaz, 1990).

In the present study, each participant was identified by a pseudonym to ensure anonymity. While reading transcriptions for the first time, the researcher also listened to the tape recordings. This process helped identify any errors in the transcription. In some of the later interviews, only relevant material was completely transcribed. Transcriptions were read and re-read before coding commenced, in order to become thoroughly familiar with the data. The constant comparison method was used as a tool for understanding the world of the leprosy sufferer, aiming at flexibility rather than formality (Anells, 1997; Charmaz, 2000). Many grounded theory studies have been criticised for being descriptive and for not providing answers to the why questions (Kendall, 1999). As the main scope of the study was to understand the sense of coherence and other coping strategies in leprosy patients, phrases that might shed light on this topic (either directly or indirectly) were collected for each case, and included in a summary compiled by the researcher. The researcher then read the interview phrases and, by means of repeated comparisons, searched for categories and subcategories. In

the search for categories and subcategories, coding and categorising of data were performed.

Coding and categorising data

Coding data is the formal representation of analytic thinking (Marshall & Rossman, 1999). The intent of coding is to conceptualise the data by analysing it and identifying patterns or events in the data. Charmaz (1995) suggests use of detailed interview quotes and examples in the body of the work. She advises that in presenting the work in this manner, the human story remains in the forefront of the reader's mind and additionally allows the conceptual analysis to be made more explicit, highlighting links between data and codes. The tough intellectual work of analysis is generating categories and themes (Marshall & Rossman, 1999). The coding initiates the process of theory development; in which new understandings may well emerge, necessitating changes in the original plan (Charmaz 2000; Marshall & Rossman, 1999). There are three steps or levels of coding, namely open coding, axial coding and selective coding.

- **Open coding**

Initial coding begins with line-by-line analysis of all the facets that the researcher finds important or interesting in the text (Strauss & Corbin, 1998). Open coding describes the process through which concepts are identified and their properties and dimensions are discovered in the data. A concept is a labelled phenomenon, an abstract representation of an object, action or interaction, or event that is significant in the data. When a code is identified, it is recorded with a short description of the noted occurrence and its position in the text. The process continues by scrutinising the rest of the text for all possible instances of new codes. The researcher compares incident by incident with the intention of establishing the underlying uniformity and its varying conditions. Codes must fit the phenomenon described in the data exactly, so they may need to be

continually fine-tuned until the fit is accurate. Grounded theorists may use hand written memoing and coding systems, and/or employ a range of software developed for qualitative researchers. As the coding progresses, the researcher derives dozens of concepts. Using the constant comparison analysis method, the coded concepts are refined, extended and cross-referenced with the data as a whole and related to each other. Once concepts begin to accumulate, the analyst commences with the process of grouping or categorising them with more abstract explanatory terms called categories. Categories portray the problems, issues, concerns, and matters that are important to those being studied. Once a category is identified, the researcher begins to develop it in terms of its properties and dimensions and differentiating the subcategories. Subcategories answer questions about the phenomenon such as when, why, how, and with what consequences (Strauss & Corbin, 1998).

- **Axial coding**

Coding is used to gain an understanding of a phenomenon and discern relationships between categories. Axial coding continues the process begun in open coding, of relating categories to their subcategories, and linking categories at the level of properties and dimensions (Mclane, Jones, Lydiatt, Lydiatt & Richards, 2003). Open and axial coding are not sequential acts, but continue together in a fluid process throughout the analysis. Strauss and Corbin (1998) recommend the use of an organisational scheme they call the paradigm model, to establish relationships between data during axial coding. The elements of the paradigm model include the identification of phenomena, conditions, actions or interactions and consequences. In coding, the categories stand for phenomena. Conditions are considered sets of events or happenings that create the situations, issues, and problems regarding phenomena. Conditions explain to some degree why and how persons or groups respond in certain ways (Strauss & Corbin, 1998). Labels placed on conditions, such as causal, intervening, and contextual,

are ways of sorting and distinguishing some of the complex relationships among conditions and their relationships to actions and interactions.

Actions and interactions indicate the activities amongst individuals, groups and organisations, and include discussions, negotiations, and actual actions. Strategic actions and interactions are purposeful or deliberate acts that are taken to resolve a problem and which shape the phenomenon in some way (Strauss & Corbin, 1998). Routine actions and interactions are more accustomed ways of responding to everyday occurrences and may include rules, regulations, policies, procedures or established protocols. The final component of the paradigm model is consequences, which might be intended or unintended, immediate or cumulative, reversible, or irreversible, foreseen or unforeseen. The paradigm model is a tool to assist investigators in systematically developing and relating concepts and categories to each other, but it need not be applied rigidly (Strauss & Corbin, 1998). Grounded theorists who do not adhere to the Strauss and Corbin methodology would not employ this model, but would allow the analysis of relationships to emerge in a less structured way through the use of questioning and constant comparison.

- **Selective coding**

The first step in theory integration is establishing the central category (which has explanatory, analytic power) that represents the main theme of the research. Selective coding is the term used by Strauss and Corbin (1998) to describe this process of integrating and refining theory. They discuss several techniques for assisting to identify the central category, including the use of storyline writing, memo analysis, integrative diagrams and review of the literature. Once the central category is identified, the theory must be refined through reviewing for internal consistency, gaps in logics, supplementing any poorly developed

categories, and reducing excess categories that do little to contribute to the theory. Since the analyst is searching for density of the properties and dimensions of a category, poorly developed categories can be saturated through additional theoretical sampling. The last step in theory building is validation, which is done by comparing categories to the raw data and/or by presenting the theory to participants for their reactions (Strauss & Corbin, 1998). Since practical circumstances made it impossible for participants in this study to verify the research findings, the results were verified by personnel from the Leprosy Mission. Theory integration occurs over the course of analysis and may not end until the final writing (Charmaz, 2000).

Integration of theory

Throughout the process of theory generation, there is interaction with the data, and the researcher uses memos to assist with the identification of emerging themes and conceptualisation of the theory (Deal-Williams, 2003; Strauss & Corbin, 1998). Three key strategies are used to develop and add density to the emergent theory (Carpenter, 1995):

- **Category reduction**
Initially a large number of categories are identified. Clustering categories and subsuming categories within larger categories can reduce these.
- **Elective sampling of the literature**
The existing literature is another form of data, and is integrated within the emerging theory, categories and subcategories.
- **Selective sampling of the data**
As the theory, categories and subcategories are identified, more data are collected from the field in order to develop and test hypotheses and uncover properties of the main categories.

EVALUATIVE QUESTIONS

Strauss and Corbin (1998) suggest the use of a specific set of questions for evaluating the adequacy of the grounded theory research process and the empirical grounding of the research. The following questions by above-mentioned authors served as guidelines for evaluating the sufficiency of the grounded theory process in this study:

- Are concepts generated? Do theoretical building blocks come from the data or some other source?
- Are the concepts systematically related?
- Are there many conceptual linkages? Are the categories well developed?
- Do categories have conceptual density?
- Is variation built into the theory?
- Are the conditions under which variation can be found built into the study and explained?
- Has process been taken into account?
- Do the theoretical findings seem significant and to what extent?
- Does the theory stand the test of time and become part of the discussions and ideas exchanged among relevant social and professional groups?

CRITIQUE OF METHODOLOGY

Reservations towards grounded theory have increased in the past decade (Benoliel, 1996; May, 1996). The main criticisms of the grounded theory method are the following:

- The epistemological assumptions have not been clearly explicated and its links with existing social theory have been decreased (McCann, 2003).
The researcher is assumed to be simultaneously objective and subjective, when using grounded theory, but the process of fulfilling this ideal, needs to be made

clearer (Charmaz, 1990). This tension can be seen when researchers using grounded theory are supposed to maintain a degree of 'detached closeness' in the field (Christensen, 1993). Researchers are expected to be objective in collecting data, but in order to obtain rich data, they need to get close to and be accepted by participants.

- Although Strauss and Corbin (1998) present a more detailed account of grounded theory methodology than the Glaser and Strauss (1967) classic version, there is still an implicit assumption that researchers have a grounding in the methods of data collection that are commonly used in this approach, particularly observations and interviews. Related to this, there is an issue regarding the simultaneous use of conflicting terminology and sociological jargon by Glaser, Strauss, Corbin and the researchers using grounded theory, which can lead to confusion and uncertainty in those researchers who are unfamiliar with the methodology. Most issues with grounded theory are attributable to misinterpretation or misuse of the approach.
- Recruitment of participants to studies can be ineffective if participant sampling is selective or purposeful. Although sampling can be purposeful initially, it should revert to theoretical sampling in response to the developing categories and theories (Holloway & Wheeler, 1996). A theory that is developed only from purposeful sampling will lack conceptual depth (Benoliel, 1996).
- A factor that can encroach on theoretical sampling is the approach to data collection. Morse (2002) suggests that there is some disagreement among grounded theorists about types of data collection that are most effective for this methodology. Benoliel (1996) claims that the use of interviews as the only method of data collection in grounded theory studies can result in researchers concentrating on the lived experience of participants instead of focussing on the social processes that take place through time. In order to have a proper grounded

theory study it is essential to have observation as well as interviews to uncover the meanings of the participants. Equally, studies may also concentrate on the immediate contextual influences on the phenomenon.

- Some researchers undertake data analysis at the completion of data collection, rather than using a constant comparative method (McCann, 2003). This undermines one of the main premises of grounded theory methodology, that a cyclical approach is applied in contrast to a linear method. It may also lead to premature closure, where researchers commit themselves to concepts, categories and theories that have not saturated in data. As a result the so-called theory is descriptive, lacks conceptual depth and has no basic social process (Hutchinson, 1993).
- Researchers who apply a mainly deductive framework, may experience difficulties in adjusting to the grounded theory approach, which requires both inductive and deductive thinking, because the former requires a greater degree of abstract thinking than the latter (McCann, 2003).

In the final chapter, the researcher will address the strengths and weaknesses of this study.

CHAPTER SIX

ENTERING THE KALEIDOSCOPE OF STORIES: THE THEMATIC ANALYSIS

INTRODUCTION

As was explained in the previous chapter, the aim of grounded theory is to explore common perceptions, thoughts and behaviours of participants who share a common experience – in this case the experience of leprosy. The theoretical framework of Sense of Coherence (SOC) was used to explore common themes in coping with leprosy, but the researcher kept an open mind when considering the unique experiences of participants and identifying possible additional themes. The following steps have thus been followed in the analysis of the data:

In order for the data to have primacy, the researcher first presents his version of a particular participant's story. The story is then analysed and illustrated with examples from the story provided to indicate how the SOC themes are revealed in the participant's coping strategies. Related themes that emerge from the participant's coping are also identified. Pseudonyms are used to protect the identity of participants. Both the common and the unique means of coping revealed in the stories of the participants will be discussed in the concluding chapter.

PARTICIPANTS

Participant A: Grace

Personal Data	
Participant:	Grace
Age:	75
Ethnicity:	Tswana
Marital status:	Divorced
Year of diagnosis:	1997
Age at diagnosis:	70

My story of Grace's story

I met Grace (aged 75) on a warm summer day at the Sonop Old Age Home in the desolate town of Brits in the North West Province. Sister Betty asked me to wait in ward E while she fetched the participant. I was so absorbed in arranging the setting that I experienced a tinge of embarrassment when I looked up and saw a woman in a wheelchair, watching me with an amused smile on her face.

What surprised me from the very start was how much younger she looked than her biological age. She told me that she had been born prematurely on 23 November 1927. Wrapped in cotton wool, lying in a shoebox, a doctor told her mother that she did not have much of a chance to live. A shy smile broke out on her wrinkle-free face when she told me that she had drunk donkey milk as a small baby and that she regarded that as the sole reason that she was still alive today. With regard to her cultural upbringing, she claims that although she is a Tswana, she did not grow up in a typical Tswana way:

Ons het op Potchefstroom oorlams grootgeword tussen die Boere. (We grew up in a clever way amongst the Boers in Potchefstroom.)

Spontaneously, a story unfolded of a woman who completed the unfamiliar JC1, 2 and 3 levels at a school in Potchefstroom. She added that this qualification was definitely not the equivalent of a proper grade twelve. As a young girl, she lived with her parents. Her father, a mineworker, drank heavily and abused her mother. Grace's mother had no other option than to run away from home, taking her little girl with her. Her mother had to work in order to look after her. When she was ten years old, her mother had to leave her to go and work in another town. She grew up with her grandmother. Grace lost contact with her father, but had the opportunity to visit him a few years after she had run away with her mother. He said he was sorry about what he had done to her and her mother, but she (Grace) "did not understand".

Many a time, as a scholar, she looked at nurses in their white uniforms and dreamed of one day healing the sick. After school in 1948, she enrolled for in-service training at the Pietersburg Hospital, where she was successful in her practical training, but failed the theoretical part. "I was too nervous." In 1952 she was appointed at the Holy Cross nursing home where she completed her training as a maternity nurse in 1955. She also worked in Louis Trichardt for six years, but after her mother died in 1964 she came back to Pretoria, where she worked in the Atteridgeville Clinic until 1972.

In 1959 she gave birth to a girl out of wedlock, her only biological child. In 1968, she married a man who had six children of his own. These children lived with them. Although she was committed to raising the children in love and to taking their interests to heart, she found it impossible to establish a good relationship with them. As a result of this unfortunate situation, her husband divorced her in 1978.

In 1973, she started working at the Westfort Hospital in Pretoria West, where she rendered service in the maternity ward, and did general nursing among leprosy patients.

From 1986 to 1992 she worked with abandoned babies at the Jabulani Children's Home. After she retired in 1993, she lived with her daughter in Garankuwa until 2001. In May 2001 she became a permanent resident of the Sonop Old Age Home.

Grace has a long history of medical problems. In 1981 she was diagnosed as a diabetic and also suffered from high blood pressure. In 1991 she presented with arthritis. From 1992, she has had constant pain in the radial nerve of her left arm. A deep concern that she might have contracted leprosy emerged from within herself, but she constantly suppressed these feelings and fears. When, in 1994, she discovered that patches on her body had no sensation she could no longer deny the truth. She was convinced that she might have contracted leprosy, and expressed her fear to her daughter. Although she consulted doctors specializing in leprosy, she tested negatively for a period of three years. But her fears soon became harsh reality. The detrimental effects of the disease were sudden. In no time, she had claw hands, lost one finger and another digit was severely damaged. She burnt the finger because she felt no warning sensation. Her left leg was amputated below the knee and her right foot drooped. After a dermatologist had diagnosed her with leprosy, she was admitted to her previous workplace, namely the Westfort Hospital, this time not as a staff member but as a patient. In later years, she suffered a seizure, resulting in bad sight in her left eye. She finds it difficult to blink her right eye and a constant pain in this eye troubles her. (Even though her eye was painful throughout the interviews and she repeatedly touched her eyebrow-ridge to soothe the pain, she showed perseverance in completing the interviews.)

It appears that Grace felt rejected by the primary men in her life, namely her father and her husband. For example, like her father, Grace's husband also tended to drink and "whap-whap" (bicker) the moment he was under the influence of alcohol. These acts led her to lose trust in them. She was not particularly tolerant of men after her divorce. She tells about a boyfriend she had after her divorce. He neglected her, and visited her only now and again. One day when he walked in the front door, she told him to leave, demanding that he never come back.

Her daughter has two illegitimate children, and previously she lived with the three of them under one roof. However, her daughter started drinking, and as a result, Grace felt more comfortable living on her own in the old age home.

On a second visit I was quite surprised at the presence of numerous mentally disabled people moving in and out of the ward during our interview. Sister Betty explained that these people were residents from a previous dispensation, when Sonop had been a home for the mentally disabled. After our interview, I walked the participant to her room after receiving the assurance that she would still get supper. Her room was small, and when she removed her headscarf, I was surprised to see that she was completely grey. She looked tired after our conversation, perhaps because she had bared her soul to me. But she was still smiling, always smiling. The sun was blazing as I sat on the bench outside, waiting for my wife to pick me up. I was joined by two men (one admitted to me that he had been a teacher before he “lost his mind”), a woman and her Down syndrome son. I was tired and relieved to leave, and although Grace stayed behind, I knew something of her went with me. My story of Grace’s story continues as we have a close look at how the three SOC themes manifest in Grace’s story. Other coping skills, not covered by the three SOC components, are also highlighted.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was manifest in Grace in the following way:

Grace’s initial reaction when diagnosed with leprosy was shock and she construed her situation as being very grave. Grace’s general feeling was that of **disillusionment**. It seemed that Grace felt that it was unfair that she had to be the chosen one to contract the disease.

It was difficult for me to accept that there were people who were employees working at Westfort Hospital for 40 years, who eventually had the privilege of becoming healthy pensioners. It was terribly painful and I prayed hard for acceptance of the disease. In the beginning I felt that life was unfair, but as time went by I felt that that was one of the things I had to overcome. I had to go through the channel.

Grace confirmed that about a month after diagnosis, the most intense feelings of devastation and grief had faded. She (Grace) felt more accepting of her disease when she made a wilful decision to accept it. She declared that the only way of making sense of the disease was to accept it. In her own words: “Once you have **accepted the disease**, you find **peace in yourself**, and that leads to healing”. She elaborated: “Yes, through all the difficulties, I’m alive and I’m thankful. Even if you are disabled, you can lead a normal life”.

I asked Grace if the disease influenced how she looks at herself in any way. The phenomenon of social comparison was evident, when she stated: “No, I am **positive about myself**. Here I am. I am alright. Even if you are disabled, you can lead a **normal life**”.

Manageability

Grace was able to manage the disease in the following way:

The **emotional support received from medical staff and former colleagues at Westfort Hospital** helped Grace enormously in managing the disease. “They helped me and **motivated** me to continue with my treatment, which made me believe in a brighter future”.

From the very start she also had a firm belief in the **prescribed medical treatment**. **Emotional support from a significant other**, her daughter, also contributed to her

ability to manage the disease. Her daughter's support was of vital importance, as some important people in Grace's life **stigmatised** her based on passages in the Bible. Grace admitted that the disease had made her **distrust people** to a certain extent, and to put her faith in God. She explained:

*My daughter was the only one that really stood by me. She will never let me down. Some relatives and people in the community stood far from me. Friends came only here and there. Family phoned, saying that they would come. Some relatives came back; others are (after eight years) still too afraid of leprosy. It showed me that people let you down when you are down. They stand far, but God is always there. I told my daughter that **God will help** me, I continually ask Him for wisdom and strength.*

Grace also paid homage to her aunt. She said that during the critical times of her development, her aunt had been her mentor. Grace's church minister also played a prominent role in helping her to deal with the emotional impact of the disease. Her colleagues felt that it was her prerogative to claim workman's compensation as a financial resource. Grace's **self-sufficiency** is apparent, as she explained that she decided not to go that route, but rather to believe in the Lord's provision.

Grace presumes that she copes with the chronic nature of the disease because she believes she is independent. She explained: "I must try and depend wholly on myself and not on others. I dress and wash myself, knit and make my own bed. I do it to feel alive".

Meaningfulness

Grace gave expression to the meaning of leprosy in the following way:

Accepting the disease, and deriving meaning from having the disease, was a **process** for Grace. She explained:

*At the time I was sitting, realizing that I was a disabled, even though in the past I helped disabled people. I asked myself, What now? I realised that I had to **accept** the disease. As time went by, she understood that it was one of the things that she **had to overcome**. I had to go through the channel.*

Grace had to escape from her “channel” of limitations to a broader **connectedness to someone bigger than herself**. There was always **hope**, and eventually she found peace in her **faith** that God wanted to use her as an example. She elaborated:

Yes, there were people who worked in Westfort for 40 years. They were healthy pensioners, but God wanted one as an example to show his greatness.

Grace commented that she realised that God wanted to show his greatness to people by inflicting this disease onto her. “We are clay and God can mould us into anything.”

During our conversation, she even went as far as describing the trauma of being a leprosy sufferer as a **pleasure, not a burden**. The meaning she derives from this disease is that it strengthens her belief in God. She explained:

*I am a person created by God to serve him. I **depend only on God**. Dependency on God comes first, then he gives me the power to be **independent**.*

She finds joy and purpose in life by believing in God. It is also obvious that Grace **discovered inner strengths** in herself. She elaborated:

*I am grateful for this condition. God is always there. Before the disease I did not understand the Bible. After repenting, I became a committed Christian. As a young girl, I was anxious, not having much knowledge about life. Like most young people, I also did not have an idea about how it would feel to be disabled. Experience is the best teacher. When the disease invaded my life, it helped me to realise that I am a person with **endurance** and **coping skills**.*

I asked Grace if she had learned anything from contracting this disease. Her immediate answer was: “**Perseverance**, and to **humble myself**.”

She stated that one cannot be arrogant if one has this disease. Grace told me about the time her leg had been amputated and she was treated unsympathetically by hospital personnel. They were not willing to help her to wash herself after she had been operated on at three o'clock in the morning. She struggled to wash herself with one hand. Grace explained: “The fact that you are lying there, feeling that no one cares, makes you humble.”

Related SOC themes

The following additional themes emerged as significant in Grace's attempt to cope with the disease:

She seemed to be able to **exert inner control**, and prevent significant control by external circumstances or her external environment. Initially, she felt out of control, but as time went by, Grace recovered and felt in control again. Even when things go wrong, she believes that she has the ability to stand, allowing herself time for the burden to pass. Grace said: “I keep up good **hope**.”

I touched on her experience of living with people who are mentally disabled. I asked her whether it is difficult to live in an environment where one is constantly confronted by mentally disabled people functioning in a way different to oneself. She told me that at times, when she is sitting somewhere, people literally fall on her. She explained that she tried to understand them, to have **compassion**. In her own words: “I have learned to keep cool.”

She was **forgiving** and did not **dwell on the mistakes of others**. For example, she states that she is not angry with the doctors who were unable to diagnose her leprosy.

Grace felt that her **cultural environment did not advantage or disadvantage her in any particular way** with regard to the handling of her disease. The fact that Grace was in the nursing profession herself helped her to distance herself from her culture, and to be more **objective about the disease**. Previously, she had talked to many patients, experiencing different reactions (for example, blaming others, suggesting they were bewitched). Given that she had fixed and lived through ideas about the origin and consequences of the disease, she was able to deal objectively with the disease. For example, she told people that there was no such thing as being bewitched. She also mentioned that she had **never blamed anyone** in her culture or her family or friends for having leprosy.

She had previously **had to cope with the trauma of other hardships**. Despite the fact that she had a **caring mother**, she was exposed to the **abuse of her father**. She coped with that, and when her husband divorced her, she reframed the loss and eventually experienced a feeling of being set free. She construed the situation as an opportunity to **grow to independence**, and developed a feeling of being able to manage on her own. Associated with that was a feeling of **resistance towards men** and the attitude of: “I don’t need men in my life.”

She came to understand that even if one is disabled, one can **lead a normal life**. She progressed to a state where she was **living positively with the disability**. She was quiet for a long time when I asked her about her experience of her body. She admitted that initially she had felt great pity for herself. Eventually she felt strong enough to help herself (physically speaking). The element of **social comparison** emerged when she explained how she had fought against the feeling of physical unattractiveness. She explained: "I told myself that there are other people who look similar to me. I'm not odd, there are other leprosy sufferers who look worse than me."

I asked her how she would describe herself, starting with the words "Grace is...". She elaborated, "...an old lady of 75 years of age; she had her ups and downs in life, but it built her up and she is strong in herself. She experienced **contentedness in suffering**. In her own words: "I feel content. Nothing to worry about."

She had **perseverance**. She felt, "Where there is a will there is a way. I hang onto things until I get it right."

She was able to **transcend** her difficulties, and believed that she had **a role to play in shaping her destiny and that of others**. For example, she was qualified as a nurse, and sees her life task as consoling downhearted people. She maintained that she contracted the disease so that she can help others medically and emotionally. She acknowledged **reciprocity of support** as she and fellow patients consoled one another.

Conclusion

After my interviews with Grace, I felt I could do a comprehensive study on her alone, and on how she is coping with leprosy. In my interaction with her, I came across such richness in the way she coped with the disease that it would do her an injustice to add anything to her voice. Perhaps her most outstanding characteristic is her ability to embrace, to accept what she cannot change. Her ability to cope could be summarised in

one expression during our interview, one single sentence, but one implying such a sense of maturity and lived-through-ness: “Once you have accepted the disease, you find peace in yourself and that leads to healing.”

Participant B: Busi

Personal Data	
Participant:	Busi
Age:	47
Ethnicity:	Zulu
Marital status:	Married
Year of diagnosis:	1970
Age at diagnosis:	15

My story of Busi's story

Busi was born in Newcastle in 1955. At the time of the interview, she was 47 years old. Even though her parents were alive during her childhood, she lived with her grandmother (a leprosy sufferer). Her mother passed away in 1996. She has two younger brothers and a sister (all who have leprosy). She has a well-developed relationship with her family. Busi had just passed standard six (grade eight) when she contracted leprosy, and she immediately left school.

Busi and her father became sick with leprosy at the same time, and both went to Amatikulu Hospital in Zululand. She moved to Durban and was institutionalised from 1970 to 1974. During this period, her father died in hospital. As her father was in a ward for the seriously ill, she did not have much contact with him. Her mother, who visited her husband and daughter regularly at that time, told her that her father had died. Busi seemed saddened when she told me that owing to the contagious nature of the disease, her mother was not allowed to touch her; not even when she broke the news of her father's death. She put her arms in the air as she exclaimed, "No, no, my mother never touched me!"

When I asked her what kind of man her father was, she exclaimed, “Ubule!” (Good!). Although her father initially wanted a boy before she was born, he loved her very much. In a practical way, he provided for her needs. For example, he bought very nice clothes for her. She describes him as a “different type of man”. He loved himself and others, especially his children. He was an affectionate man, hugging and kissing his children. He was not educated, but he focused on doing things to “better” himself. He was, for instance, interested in Zulu dancing and singing. Her mother also regarded the development of her children and their happiness as very important. Busi therefore feels that she developed her ability to care by having the perfect example in her parents. In Amatikulu she was very sad when her father died, especially as he had protected her against adult men who wanted to exploit her sexually.

In 1974 she was discharged since she was much better. She received medication from Dr S, as he was connected to the Amatikulu Hospital. But probably from a lack of proper treatment, she slowly but surely developed claw hands after she had been discharged. Her nose collapsed, and a toe of her left foot was amputated. A loss of sensation caused serious damage to her hands as she burned them repeatedly. Busi felt that she could not marry a man who suffered from leprosy, as the disease would have “continued.” She had Buthe (a good and healthy man) as a companion for a long time, but only married him in 1990. She did not want to marry him at first because he did not have a job, and could not pay lobola. Out of this relationship, two daughters were born. One (19 years old) has a child of 11 months, and the other daughter is 11 years old. According to her, Buthe is a strict father, and looks after the children well. There are quite a number of similarities between him and her father. Generally speaking, she and Buthe have a good relationship. Presently they live in a squatter camp, called Ezimangweni.

When she contracted the disease, she felt heartsore. She was focused and felt so strongly about her goal to get an education that she did not even want to waste time with boyfriends or to get married. My story of Busi’s story continues as we have a close look

at how the three SOC themes manifest in Busi's story. Other coping skills, not covered by the three SOC components, are also highlighted.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was manifest in Busi in the following way:

I was inquisitive to find out how Busi conceptualised the disease as a teenager. Although she experienced **confusion**, and applied **defense mechanisms**, for example **denial**, in dealing with the emotional impact of the disease, her ability to cope was amazing. She described her experience:

*I did not know the diagnosis of my disease, but realised that people (like our neighbours) were laughing at me. When I was taken away to Amatikulu hospital, **the diagnosis of my disease was still kept a secret**. In the hospital, my mother was not allowed to give me anything, a parcel or so, like food. The nursing personnel knew my diagnosis, and they were not kind; they even thought that the disease was in the ambulance. The physical pain was very bad before, but I **tried to make myself forget that I had leprosy**. When I was small, I told myself that **I just had to accept it**; that I must do everything in my power to **help myself**. Amatikulu Hospital was fenced like a prison and that made me feel afraid. During that time, I had the desire to socialise with non-leprous people.*

The phenomena of **social comparison** and refusal to be in a **patient or victim role** came into the equation as she stated:

*I don't believe in separation, but I told myself that **I am the same as other people**. I know myself well; I can do anything, at least anything other*

*people are doing. **The moment you see yourself as a sick person, you don't cope.** I can do anything that other people do.*

Although she had experienced severe physical and emotional pain in the past, she described herself as someone who did not have many problems (like Grace). She **focused on her strengths**, and expressed **self-reliance** as she believed that she **had to do everything in her power to help herself**. At the time of our interview, Busi felt **positive**: “Not everything is out of control; everything is all right. My future is good. I can see where I am going.”

Manageability

Busi was able to manage the disease in the following way:

She believed that medical treatment and a divine intervention were significant factors in her attempts to deal with the disease. In her own words: “What helped me a lot to deal with the disease, were **medication** and **prayer**. I also **know myself very well** and **I can see where I am going.**”

She believed that God and **significant others**, her family of origin, also helped her a great deal in managing the disease. She elaborated: “My mother never **rejected** me and my leprous father.”

Her father also played a major role in her ability to cope with the disease. When I asked her what kind of a father he had been, she exclaimed, “Ubuhle!” (good). She elaborated:

In the beginning, he wanted a boy, but he loved me. He hugged us, bought good clothes and was very good to me. He was another type of man. He was not educated, but he wanted to do things, for example, he was

interested in Zulu dancing and singing. In Amatikulu, I became very heartsore about my father as he became very ill. He wanted to protect me, seeing that there was a problem with men who wanted sex.

Busi showed self-confidence, was **independent**, and her approach could be described as **active**: “I am sewing, making aids badges, and have a creche. Everything is **under control** and all right. **I trust in what I am doing.**”

It was also obvious that she experienced an abundance of **emotional support from her husband**. She elaborated:

In the beginning I felt that I could not marry a leprosy man; the disease would have continued. And he also did not have a job and he could not pay labola. But Buthe is a good man; he's the same than my father. He is a strict father, but he looks well after his children. He has a good relationship with them.

Busi also had **social support from friends**. At the same time, she was able to reciprocate their kindness by **transcending her difficulties** and supporting her friends. She explained:

I have good friends, especially Gloria and Sabi. I met Gloria when we were children with leprosy in Amatikulu. Sabi, who also contracted the disease, was a teacher at Amatikulu. Her friends feel that she helped them a lot. Sabi even asked her to help her with her twins. There was a time that Sabi did not have any income. Buthe and I decided to support her financially.

Meaningfulness

Busi gave expression to the meaning of leprosy in the following way:

She touched on the **negative social voice** of the community when she stated: “People believe you are useless if you get this disease. I’m **not useless**. You know, people can’t believe I have such a beautiful, big home.”

Busi was therefore able to **transcend** the **stigmatisation** from the community. In fact, the process even **empowered** her as she described that she was able **to derive meaning in her suffering**: “Leprosy made me **stronger**.”

Busi was **ambitious** as a teenager. She explained:

*Although I was **bright** at school, I wanted to get to standard ten to become a nurse. The disease broke my plan. By getting educated, I wanted to show to my parents that I appreciate what they did for me.*

Busi can therefore be described as a person who is **not self-centered**, but one who has a **social conscience** and a desire to contribute to the well being of others.

Although the idea of having leprosy was literally unbearable initially, she felt that her life was fulfilling. She mentioned her good marriage and the absence of abuse in her family as examples. Busi probably contributes immensely to the well being of her family, as she is **generative, goal-orientated** and **responsible**. In her own words:

If, at times, I look at a person who does not have leprosy and feel hopeless, I rather prefer to focus on my aim of having a good home and a good life with my children. I must look after my children all the time. They

are my responsibility, especially because Buthe is not working. I learnt responsibility from my parents.

Related SOC themes

The following additional themes emerged as significant in Busi's attempt to cope with the disease:

- **Secrecy and deception regarding the diagnosis.** In Busi's case, both these two scenarios were beneficial. At the time she contracted leprosy, Busi did not experience rejection from the community, because nobody knew about the diagnosis. People were not aware of why she had been taken away so abruptly. Her parents decided to keep it a secret. The fact that the community did not know that she had the disease, made her feel free. By not revealing the diagnosis, Busi had the opportunity to adjust to the reality of the disease without being exposed to possible stigmatisation. However, as time went by, more and more people discovered that she had the disease. When this became widely known, she did not experience any stigmatisation. That assisted her re-integration into the community.
- **Non-blaming.** She **did not turn any negative feelings upon** other people or objects. Although there is a great possibility that she might have contracted the disease from her grandmother, she was not angry with her, and their relationship remained stable.
- Busi **applied her entrepreneurial skills.** Although she was never formally employed by an institution, she started a crèche in 1991. Some parents are not in the position to pay the required crèche fees but others pay R50 per child per month and this serves as an income for Busi. As The Leprosy Mission assisted

her in learning how to sew, she makes bags, Aids badges and sells them for an income.

Conclusion

Perhaps if your father is dying in another ward in the Amatikulu “Prison” and your mother is not allowed to touch you, your only option is to try and remember how your dad looked when he was dancing and singing passionately, or to try and “forget” that you have leprosy. However if, as an adult, Busi was able to convert passive denial into active acceptance, then perhaps it was why she could maintain: “I am the same as other people, in fact, I am better”. Perhaps only then did it become possible for her to transcend and to give; to be a good parent, like those she had had. Perhaps it is only then that she could turn around and look at the researcher, saying, “You know there is a verse in the Bible, I don’t know where, that says that you must help others.”

Participant C: Sara

Personal Data	
Participant:	Sara
Age:	60
Ethnicity:	Zulu
Marital status:	Married
Year of diagnosis:	1993
Age at diagnosis:	51

My story of Sara's story

Sara, a Zulu participant, was born on 21 September 1942 and was sixty years old at the time of the interview. She grew up at Bergville near Ladysmith. She completed standard eight (form 2) in this little town. Sara would have loved to continue with her education, but due to financial restraints, was not able to do so. Sara had two brothers who had passed away and three sisters who are were still alive. As her mother was employed as a domestic worker in Ladysmith, she grew up with her sisters and grandmother. They set a good example to her of how to look after children. She did not have the privilege of growing up with a father. Sara was nine months old when he died from ill health. She told me that she was twenty when she moved to Umlazi, where she is living to this day.

After completing standard eight, she left school to start work at a crèche at Bergville as an assistant teacher, doing mainly teaching and cooking. Thereafter she was a domestic worker until she contracted the disease in 1993. Initially, she felt weak and ill, which led to her struggling to do her tasks the way she had always done them. Her employers were not happy with the fact that she had ulcers, and eventually she lost her job. At that time, which was a difficult period for her, she enjoyed reading the Bible. She stated, "I stay with the Bible. I love God. I like going to church, watching television, reading

newspapers, especially 'The Mercury'." Sara has no specific disabilities, although she suffers from cramps in her hands. Her hands look peculiar and she experiences loss of sensation in both feet.

At the age of 23 she got married to Tom, the only husband she has ever had. He was a kind man initially, but unfortunately he drank too much. He worked as a machine operator in a steel factory. Sara had a well-developed relationship with him. At a time he began, according to her, "talking too much". She was heartsore about their relationship problems and used to cry a lot. He passed away in 1998 as a result of a stomach ulcer. She had eight children, of which four were boys and four girls. She lived with three of her children. The eldest, 26 years of age, was studying at a Technikon. The second born was in grade 12, while the younger one was still a scholar, aged 11. Two of her daughters were married, and three of her sons were taxi drivers.

With a soft light in her eyes, Sara smilingly said at the end of her interview, "I see that there is care, people loving us." My story of Sara's story continues as we have a close look at how the three SOC themes manifest in Sara's story. Other coping skills, not covered by the three SOC components, are also highlighted.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was manifest in Sara in the following way:

When Sara first fell ill, she was admitted to the King Edward Hospital. Thereafter, she was diagnosed by Sister Y from The Leprosy Mission. In the course of the disease, she was **uncertain** and did not know what was happening to her. Initially she was **upset** and **did not understand** what leprosy was all about. Her only source of information was the Bible, and she explained her feelings at the time:

*I was upset and was **unsure** what leprosy was all about. I looked at myself and **felt sad** when the colour of my skin became black. I looked like a grandmother. I also read in the Bible that one gets ulcers and that one's meat would fall down.*

Fortunately, Sister Y shared **medical knowledge** with her, and that set her at ease. She explained:

*Sister Y gave me a book on leprosy. I followed the instructions and when the sores disappeared I knew that I was going to be healed. I **don't fear** leprosy anymore. I use **medication** and I don't have the same idea as in the Bible. I saw that the meat was not falling down.*

After she recovered, she was **selfconfident**. Patting herself on the chest, she maintained:

*This disease gave me an **open mind** as I knew that I just had to **accept** the disease. I am patient when I am facing difficulties. **Patience** helps you to think and to make a good decision. People make mistakes when they make quick decisions. After I got the treatment, I knew that I was going to be better. **Life is not bad; I feel free.** I am **still standing**, and I love myself.*

Manageability

Sara was able to manage the disease in the following way:

With the onset of the disease, she was motivated by family members to pursue the traditional healing route in order to solve the problem. Presently, she shows **resistance**

towards traditional healing methods. She laughed when she described her experience:

*Once you tell people that you have the disease, they send you to the sangoma. He puts strange things (like skins) on your body. He also wanted to force me to drink goat blood. **My culture did not help me, it was really a scary experience.***

Her husband was her main source of support as he was loyal throughout the course of the disease and never threatened to leave her. She felt that leprosy had no a distinct influence on her sexuality or married life. Today, thinking back to those days with Tom, she felt “all right”. When Tom was alive, she was dependent on him. When he passed away, she realised that she had to be **independent**. She explained:

*I did not have parents and I just knew that I had to be independent; that I had to solve my own problems. I should not even depend on my children, just on myself. I learned that from my grandmom. She taught me **to look after myself**; taught me **to protect myself** against boys. Told me not to be a beggar, but to work independently. If I really don't know how to deal with a difficult problem, I ask someone to help me. But it must be the right person.*

Sara believed that, practically speaking, one needs to be independent. In her own words: “Sometimes I need other people; sometimes I cannot wash with one hand, but if there is not anyone then I try to wash myself”.

As time went by, she believed more and more that **women are more reliable and self-sufficient than men**. It was also obvious that she believed that women should be given the opportunity to have the **freedom of making decisions independently**. She elaborated:

Women are greater than men, they have better decision making abilities. Many times, homes are without men. Where are the men? They're gone. Where there is no mother, there is no provision.

Sara managed the disease as she was **positive** and **solved problems actively**:

*I look into my future and **I see success; things are coming all right**. It is very **nice to be alive**. I'm doing well; sewing and selling; getting a bit of money. Sometimes I'm short of material, but I'm **trying**. My children are doing well at school without a father. If there are problems, one must not leave it. You must solve it, otherwise it will stay there waiting for you. I have got **hope** that things that I do, will be a success. I also believe that **things will work out as expected**.*

Sara believed that God did not create her to have this disease; rather, he created her to **'fight'** it and **to overcome her suffering**. She believes that demons (bad spirits) gave her the disease and that she was actually supposed to deal with it in a religious way. She elaborated:

*There were things that happened when I did not believe. Like going to Sangomas; I stayed there for eight months; using muti. I have decided to **trust God**. We don't see God, but we see his actions. He helps me; when you pray everything happens. I'm **not powerless**. I **have control** and I **feel all right**. I'm not sick. Sometimes I feel pain in my bones, but I **have faith**, and I ask God to help me. Thereafter the pain disappears. I'm not going to get sick again; I come regularly for check-ups.*

Meaningfulness

For Sara, the meaning of the disease lay in the fact that leprosy did, in effect, lead her to believe that she has the ability to cope with diseases. She believed that leprosy is very different to other diseases. According to Sara, the severity of the symptoms of leprosy distinguishes it from other diseases. She elaborated:

*I look into my future and **I see success; things are coming all right.** It is very **nice to be alive.** I'm doing well; sewing and selling; getting a bit of money. Sometimes I'm short of material, but I'm **trying.** My children are doing well at school without a father. If there are problems, one must not leave it. You must solve it, otherwise it will stay there waiting for you. I have got **hope** that things that I do, will be a success. I also believe that **things will work out as expected.***

Sara showed commitment to her children as she defined her **goal in life** as:

To make sure that I have good things and that my children lead good lives. I would like to care for them more, for example, provide them with good food, especially now that their father has died.

She elaborated on her purpose in life by stating that she “**wants to enjoy being alive**”.

Related SOC themes

The following additional themes emerged as significant in Sara's attempt to cope with the disease:

- She **retained anonymity about her disease.** Sara confirmed that her family and church people were the only people who knew that she was ill. However, not all

knew that she had leprosy. She believed that once you tell people that you have this disease, they send you to a sangoma who practises harmful therapeutic methods.

- Sara admitted that she **took great care in the medical treatment of leprosy**. When I referred to the photos of deformed patients on the wall, it triggered strong feelings within her. During the course of our interview, Sara turned around a few times to look at the photographs. I asked her what advice she would have given those in the photographs on how to survive. Her response was that she would have told them about the proper medical care that should be taken for the ulcers. She would also have liked to take care of their physical problems, for example: “I advised a patient with a rotten foot. You must clean your foot so that it does not get amputated. The ulcers will recover.”
- She is **able to forgive**, and does not spend emotional energy on harbouring resentment towards people. As an example, although her sons were successful in business, they did not assist her financially. Sara was not angry with them as she believed that God knew that they would change and that she is under an obligation to pray for them.
- She was able to **transcend** her difficulties, and believed that she had **a role to play in shaping her destiny and those of others**, for example: “I **love people** and I wanted to **do something to help people**; therefore, I wanted to become a nurse. Unfortunately, I could not continue with my education, but I can still organise a stokvel, sew, work with the community and help people to help themselves.”
- Her **ability to practise entrepreneurial skills** therefore also emerges. Her success is apparent, as she lives in a “good house” in a squatter camp.

Conclusion

At the end of our interview, Sara implied that she had heard a positive social voice, as she mentioned that she had enjoyed the interview. In her own words: “It is nice to be here.” It would also have been nice if Sara could have:

- grown up with her parents.
- had a husband who fulfilled all her emotional needs.
- trusted men.
- had a father for her children.
- had the finances to become a nurse.
- had all her children support her financially.
- experienced the absence of demons who give people leprosy.

However, it is really ‘nice’ to have people like Sara in our midst to serve as an example of how to see perfection in imperfection; to serve as an example of how to feel that it “is nice to be alive”.

Participant D: Mali

Personal Data	
Participant:	Mali
Age:	52
Ethnicity:	Zulu
Marital status:	Single
Year of diagnosis:	1952
Age at diagnosis:	2

My story of Mali's story

Mali is a Zulu woman who was born on 5 September 1950 at Empangeni. At the time of the interview she was 52 years old. She contracted leprosy when she was about two years old. Her father (a farmer) and mother (a housewife) died at more or less the same time that she was infected with the disease, so she had never known them. In 2001 her brother died at the age of 60, from TB. Her two older sisters raised her. Although her sisters looked after her very well, she missed having a father and a mother.

Mali was severely disabled. She had claw hands, her right leg had been amputated, and she had only one toe on the other foot. When she contracted the disease, her sisters took her to the Ugwelezane Hospital. There a doctor diagnosed her with leprosy and she was taken to Amatikulu Hospital. She remembered very well the trauma of being separated from her sisters. She attended a school for children with leprosy (near Amatikulu). She was deformed as a little girl: her hands became clawed. At the age of 39, her leg was amputated. Presently she earns an income by weaving mats; a skill that she learned in Clarewood Hospital when she had her leg amputated. Mali mentioned that if she were able to choose a specific career, she would have become a professional wool weaver.

Mali had only one child who died of jaundice in July 1974 at the age of one-and-a-half months. She never married, and while she was in a relationship with the father of her child, he became sick and died from heart problems. Her partner never threatened to leave her because of leprosy. However, Mali did not develop a trusting relationship with him, and she did not feel comfortable with the idea of marrying him. She claimed that she did not need a man's support. Losing her only child was much more painful than losing her partner. She felt much better now. She confessed that if she had not believed in God, she would not have been able to work through the grief of contracting leprosy and losing a child.

Ms X, a nursing sister from the Leprosy Mission, shared with me that a month prior to our interview, Mali had been harassed by two men. In the process, her leg was broken. Ms X was quite impressed by the fact that, all on her own, Mali had laid a charge at the police station and had consulted an attorney about this matter. In a strange way, I was not surprised. I knew she would do just that.

My story of Mali's story continues as we have a close look at how the three SOC themes manifest in Mali's story. Other coping skills, not covered by the three SOC components, are also highlighted.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was manifested in Mali in the following way:

Initially, Mali experienced intense emotional and physical agony as a result of leprosy. In her own words: "I was **unable to understand** what the disease was all about. Now I'm much better; I have **accepted** that **God** touched me."

It was obvious that the **medical and occupational treatment** that she received helped her to understand the disease in a different way. She also described her **process of acceptance** of the disease. She elaborated: “God knows what happened to my life; I can’t deny; I must just accept that God gave me leprosy.”

She felt much better at the time of the interview, as she had decided that: “God touched me.”

It appeared that Mali had a **positive self-image**. She believed that the disease had not influenced the way in which she looked at herself negatively, or **in comparison with others**. In her own words: “I **accept** the way I am; I feel **the same like other people**; I’m not a **loser**.”

Manageability

Mali was able to manage the disease in the following way:

The **medical treatment** that she received from medical personnel at Amatikulu Hospital helped her in coping with the disease. She felt that by enjoying very efficient patient care, she was able to manage the disease more effectively. Mali affirmed that she had gained **proper medical knowledge** about the disease and accompanying treatment. She described her experience:

In Amatikulu, all the patients and medical doctors came together in a hall. There they examined all the patches and nodules, and provided medication for six months. At a later stage, blood tests were done, and patients were told to stop or continue with treatment.

She stated that the thought of being treated by Christian doctors helped her very much. She felt that she also handled the disease by “putting my trust in **God**”. She elaborated:

*God knows what happened to my life, I can't **deny**, I must just **accept** what comes from God. He gave me leprosy. God wanted to show his power by bringing this disease to me. Satan did not give me leprosy. God is showing me that I must love him more. I am **not angry with God**. I **accept what I am**.*

Mali managed with the disease by receiving **social support from significant others**. She explained:

Without a father and mother, there was a gap. I missed them. Fortunately, my sisters were looking well after me. For example, if they did not take me to hospital, I would have been gone.

Despite her childhood dependence, Mali's outstanding characteristic is her "**independence**". In her own words: "I must be able to make my **own plans**. If I have no tea, I must get oranges and sell it to buy sugar. I even built my own house."

She is **active** and not dependent on others, especially not on a partner. In our interview, her gender prejudice emerged. It was obvious that she had **reservations about men**. She remarked: "I don't need a man's support. Men give problems, and therefore I decided not to get married. I will have high blood pressure if I get married."

Meaningfulness

For Mali, the meaning of the disease lay in the fact that it gave her the opportunity to experience **spiritual enrichment**. In her own words: "God wanted to show his power by bringing this disease to me. God is showing me that I must love him more."

Furthermore, the disease helped her to be **positive** and to be **dependent on God**. She claimed: “My **future is good**. I see where I am going. I ask God all the time to give me what I need.”

A sense of **empowerment** also came from the process of embracing her diagnosis. She explained:

This disease helped me to be clever, for example, I learned skills at Amatikulu. My goal is to do what God wants me to do, then things will work out as it should.

Related SOC themes

The following additional themes emerged as significant in Mali’s attempt to cope with the disease:

- **Blaming** of others was absent. For example, she was not angry with the medical personnel who had not given her proper treatment. She forgave them and exclaimed that: “they tried everything in their power to help me.” Furthermore, although she believed that God had given her the disease, she was not angry with him.
- **Perseverance since childhood**. Mali had to deal with intense emotional trauma from early childhood. Yet she was able to overcome the associated trauma of the disease. She explained: “I was separated from my sisters when I was taken to Amatikulu Hospital. I was deformed and very small, I remember that day well. But I am **fine** now.”
- Mali developed her **entrepreneurial skills**. She progressed to standard four and had never been employed by an institution or an employer. The only training

opportunity she had had to generate money was at the Clarewood Hospital where she learned to weave when (ironically enough) her leg was amputated. To earn an additional income, she stayed at Ntuzuma (near Kwamashu) with three children of neighbours, who were working at a restaurant in Durban.

- Mali preferred to **focus on her inner strength** instead of her disabilities. She was, for example, visibly proud of her ability to weave. I asked her how she managed weaving with claw hands. She said: “You must see me in action.”
- **Secrecy** and deception regarding the diagnosis.
- She had to **overcome previous losses**. Both her child and her partner died. The only way of dealing with such emotional pain was to overcome it by “having faith”. I asked her to elaborate, but her answer was simple: “God touched me.”

Conclusion

While I was listening to Mali’s story, the biblical words “We come into this world on our own, and we leave this world on our own” came to my mind. If a two-year-old psyche is forced to deal with the reality of being orphaned, perhaps that realisation need not necessarily lead to the bruising of the child, as has been suggested by some theorists in the psychology field. Perhaps the flipside of the coin applies: perhaps it may create a hardiness, a deep insight that, ultimately, nobody should try and do for you what you cannot do for yourself, or for that matter, stand in your way if you are looking after yourself. As Mali’s bullies would learn in the long run, “She is definitely not the kind of woman any man should try to mess with.”

Participant E: Ziqie

Personal Data	
Participant:	Ziqie
Age:	32
Ethnicity:	Zulu
Marital status:	Single
Year of diagnosis:	1983
Age at diagnosis:	15

My story of Ziqie's story

The interview with the previous participant took much longer than I had anticipated. After the well-dressed Ziqie had travelled about 200 kilometres to see me, she was forced to spend an unplanned night at Umlazi in order to be interviewed. The Leprosy Mission has a policy of ensuring that patients do not become dependent (particularly financially speaking). In other words, interviewees are not remunerated. Her motive for being interviewed was obviously not a financial one. I was amazed at her patience.

Ziqie was born in 1969 in the Msinga area, which is a rural area at the foot of a mountain which falls under the rule of a chief. She lives still there. She was shy during the interview, and looked much older than her 32 years. The expression on her face correlated with the description of *leonine facies* in chapter two.

When Ziqie was still very young, her father disappeared to live with a younger wife in Johannesburg. At that time, he was working in a sweet factory. To Ziqie, his leaving was an intensely painful experience. But, to her joy, it was not long before he was reconciled with the family. In 1993, he died of tuberculosis at the age of 59. Ziqie told me she has three older sisters, but she began to cry when I asked her about her mother.

I handed her my handkerchief. I asked her why she cried when she referred to her mother. Her response was that she always cried when she thought about painful things from the past. Her mother suffered intensely.

At the age of two, Ziqie developed a patch on her cheek, but was not diagnosed. In her first year at school, she fell ill after she had been attending school for only a short while and the principal chased her away. She thus received no formal schooling, and has never been employed. When Ziqie was seven, she developed claw hands. At the age of 12 she was taken to a general practitioner who told her mother that he could not help her with the disease. He advised them to consult a witchdoctor. She laughed, "The practitioner was a demon, not a doctor." Besides the visit to this witchdoctor, her family also took her to a church in Clermont where her body was washed in front of other church members. At that time she suffered a great deal, as she still had claw hands and was unable to walk. She resisted the cultural way of handling the disease strongly.

When she consulted a "cheeky" doctor at a clinic in Pinetown, he insensitively asked her where on earth she had come from, having a disease that did not exist. He (the doctor) called an ambulance to take her to the King Edward Hospital. Ziqie seemed deeply saddened when she said, "I looked like an animal. The sisters in the ward did not want to come near me. They were too afraid to touch me." Whenever people looked at her she cried inside. However, at the time of the interview, she stated that she was at peace with the appearance of her face.

The doctor who treated her in the King Edward Hospital was an improvement on the one in the Pinetown Clinic as he showed greater sensitivity. He called other doctors to examine her. Eventually, they diagnosed leprosy, but the diagnosis was not revealed to her. She was immediately taken to the Prince Mshiyeni Hospital where treatment was begun. This was in the year 1983, and she stayed at this hospital for eighteen months. The first time she came to realise that she had leprosy was in 1987. Due to deterioration in her condition, Ziqie was re-admitted to the Prince Mshiyeni Hospital in 1987 and

discharged again in 1988, going back to Msinga. Ziqie had scars on her hands. She revealed that she had had claw hands before, but that they had improved dramatically because of the fact that she exercised them religiously. I noticed that she was wearing orthopaedic shoes. Aware of my curiosity, she smiled and added that her toes were also slightly clawed. She told me about the ankle problems she experienced.

At the time of the interview, she was still living with her mother and her unmarried sister. Ziqie never married and has no children. She has three intimate friends. Her hobby (and source of income) is doing handiwork. A few years before, the Leprosy Mission had arranged for her to attend a sewing course at the Kwazulu Technical College. By sewing and selling school uniforms and trousers, she made a good living. Although she had no formal education, she believed that she had a future in being successful in her handiwork. Ziqie did not want another career as she felt she had made a success of this one. She just laughed when I suggested to her that her business must be doing well considering she is the proud owner of an expensive cellphone.

She decided to establish a “disability group” in order to discuss with other disabled people ways and means of earning money, and to introduce a platform where they could encourage one another. The idea started after she had met a leprosy patient in a wheelchair and had talked to her. The woman conveyed her fear of people who did not believe that she could work efficiently. Ziqie motivated her and soon other disabled people joined in. They started sewing and making hats, mats and birthday cards. Ziqie decided not to establish the group for leprosy sufferers exclusively as “it would have been difficult to get new ideas.” She found it very rewarding to teach people to work profitably with their hands, helping them to be successful.

Ziqie was not involved in a relationship with a man at the time of the interview, and therefore received no financial assistance from anyone else. Sister E told me that, at times, Ziqie felt angry with God about the disease.

I was moved by Ziqie's story and felt the need to tell her how her pain had touched my heart. After the interview, I told her to keep the handkerchief as a token that there are people who care for her. Shyly she showed deep appreciation. When she left the room, her back was straight, and in her hand she clutched the piece of white material.

My story of Ziqie's story continues as we have a close look at how the three SOC themes manifest in Ziqie's story. Other coping skills, not covered by the three SOC components, are also highlighted.

Emerging SOC themes

Comprehensibility

Ziqie gave expression to the theme of comprehensibility in the following way:

Initially, it was painful to be **uncertain** about the disease. Ziqie recalled **rejection** associated with leprosy, especially the awful day the schoolmaster chased her away. "I was **heartsoresore** and **angry**, because I was young."

She described how she **fought** against feelings of **pain** and **weakness**. She confessed that she had always experienced some sort of **control**. Her path to understand what leprosy, both physically and emotionally, and subsequent healing, "was all about" was, however, a **process**. Feeling **exposed** and **humiliated** was dreadful, but the incident with the headmaster (amongst others) helped her to **transcend** and to convey a **positive** message:

*I am no longer angry with the doctors and the schoolmaster. My aim is to think about the future. One must put the **past behind**, and have **fighting spirit** in your heart. Although my body is damaged, I rather prefer to think about my future.*

Other vulnerabilities, such as **physical appearance**, seemed to be of less importance after Ziqie had gone through her process. She claimed:

For women, their faces are the most important part of their bodies. When I got the disease, it was terrible. My heart was very sore when people looked at me. I know that I am not very attractive; for example, my older sister looks younger than me, but I love myself. I'm okay, my face is all right.

After Ziqie had looked at the pictures of the leprosy patients on the wall, she added:

*I was like them, and if I had the opportunity to talk to them I would have loved to show them my picture, and tell them there is **hope**. I would tell them that **God** who created us, loves us, and if you trust him, you will get right. I will tell them your life is not finished, you are still **alive**.*

Manageability

Ziqie was able to manage with the disease in the following way:

She dealt with the disease by being **independent**. She had not even applied for a disability pension as she had experienced problems with the payment of the fund and had decided to leave it. With regard to dependence on other people, she argued:

*I will not depend on anyone, just on myself. I don't want my mother to support me. I want to help my mother; she worked too much in the past. I **won't depend on a man** - if he drops dead, I will fail. I will only **trust God**. Things are **under control**, but I cannot do things without God's power. I ask him to help me to get control. If God was not there, even the doctors would not be able to help me. I asked God to help me to **forget about the past**, and he helped me.*

It was obvious that Ziqie had deep-seated reservations about men. She stated that, at 32 years old, it would be difficult to share her life with someone else. She suggested: “A man will cause trouble. Sometimes married women find it difficult with men. They (men) are too wise.” She had no distrust in her ability to raise children. She explained: “Women know how to raise children; men know how to work and earn money. Women know much better than men what is happening in their homes.”

Ziqie suggested furthermore that she was not less effective than men and was more than capable of being **assertive**. She claimed: “Nobody can **move** me. Nobody can take my heart, I am **strong**.”

Ziqie also coped with the disease by being **active**. She added:

*When the pain comes, and I feel life is **unfair** and I feel **weak**, I tell myself to try and **'go forward'**, rather than to **'come down'**. When weakness comes, I tell myself to do something with my hands. I tell myself if I allow myself to sit down, I will get sick.*

She knew that **medication** and **significant others** had helped her a great deal in the past, and had also given her peace of mind. She maintained: “I was never rejected by family members, and my family was very strong in handling the community.”

Elements of **self-sufficiency** and **positive social comparison** emerged when she claimed:

*Although others have more compared to me, I feel happy with what God has given me. I am **satisfied** with what I have. Although I don't have an education, I'll make sure that I am successful with for example my handiwork.*

Meaningfulness

Ziqie derived meaning from the disease in the following way:

***God** wanted to show his power to me; to let me praise him. God never brought this disease to me. This is the Devil. God wants me not to be **angry** with him. He wants me to **fight** this disease. He wants me to be **thankful** to him for the things he is giving me. God created me to live in this world. He does not want my body and soul to **suffer**.*

Furthermore, she was able to **transcend** her circumstances. She believed: “I don’t want another career, I feel successful. I want to teach people to work effectively with their hands, so that they can be successful.”

Related SOC themes

The following additional themes emerged as significant in Ziqie’s attempt to cope with the disease:

- **Perseverance since childhood.** Ziqie was exposed to intense emotional trauma ever since early childhood. Yet, she had overcome the physical and psychological impact of the disease, as well as withstanding the strongly negative voice of society.
- Disbelief in **traditional healing methods.** Ziqie showed strong resistance to cultural healing methods.
- An ability to make **contact with feelings**, whether those feelings were negative or positive. During our interview, she started crying over her mother. I probed her,

and her explanation of her behaviour was: “I have this problem that I cry when I think about the past. If I remember painful things, I cry.”

- Ziqie developed her **entrepreneurial skills**. She had no formal schooling, and the only training opportunity she had had was at the Kwazulu Technical College where she was taught to sew. She grabbed the educational opportunity and the success that she had with her business was reflected in her lifestyle. She was, for example, the proud owner of a cell phone. She was also able to **transcend** and to **uplift others**. She claimed:

I have a future, I'll make a plan. We have a disability group where we discuss different ways of earning money. I started the group when I saw a leprosy patient in a wheelchair. I talked to her and she said that she was too afraid that people will not believe that she can do work. We started sewing hats and mats. We also made birthday cards. I encouraged her and others joined in. I have decided not to have just a leprosy group. Then it would be difficult to get new ideas.

Conclusion

Ziqie's answer lay neither in the voice of a principal who chased her away, nor in the voice of a traditional healer who looked confidently at his bones. It did not lie in the voice of a minister who spoke with certainty while he was washing her body either. It lay in a gentler child's voice that told her not to give up, whilst looking at her seven-year-old clawed hands, a voice that told her not to “go down” but to “go forward”. These words are simple enough for a seven-year-old to understand, but in practice, they are far more encompassing.

Participant F: Peter

Personal Data	
Participant:	Peter
Age:	66
Ethnicity:	Coloured
Marital status:	Married
Year of diagnosis:	2002
Age at diagnosis:	65

My story of Peter's story

I met the humble Peter at his house in Mariann Heights (a suburb of Pinetown) (See Image 6.2). The environment was very hilly, and there were many trees, especially on the upper slopes. Peter lived at the bottom of the hill. A few steep steps took one downwards before reaching his house (See Image 6.3). During rainy periods, Peter's house is surrounded by water, which creates problems at times. He still has to do some concrete work to ensure proper drainage.

Due to the disease, he finds it difficult to blink. His eyes became teary, which he found to be uncomfortable at times, and he had to manage with that during the course of the interview.

Peter is 66 years old but does not look it. He is coloured and was born on 4 October 1936 on a farm near Harding (a town close to Port Shepstone on the way to Kokstad) (See Image 6.1). He was the only child of his father (who was a painter) and his mother (a washerwoman on a farm). Although his father drank too much, they never experienced any serious familial problems. All his life, he had a good relationship with both his parents. His father died in 1971 and his mother in 1984. His mother lived with

him and his wife (Janie) until her death. Peter's mother was a perfect example of inner strength. She encouraged him, told him that he had to be strong and that there would always be wonderful things ahead when he least expected them. She also supported him during his school years in Harding, and he progressed as far as standard six (grade eight). After his father fell ill in 1954, Peter had to support his mother and started working as an apprentice in a butchery at the age of fifteen.

He worked there until 1958, and thereafter in butcheries in Kokstad and Durban. He retired in 1982 at the age of 50, suffering from high blood pressure. Although he did not receive any formal training, he went into the ministry full time, becoming a minister of the South African Evangelistic Mission (SAEM). He finally retired at the end of 1999.

Peter got married to Janie when he was 22 years old. They have been happily married for the past 43 years. He explained that, as Christians living according to biblical principles, he and Janie never experienced serious marital problems. Young missionaries helped them to convert their lives by giving their hearts to the Lord. Their advice to Peter and Janie was to communicate effectively, which they did, even as a young married couple. A solid foundation of effective communication with her husband also helped Janie to form a thorough understanding of the impact of leprosy. The decline in sexual activity in their marriage, for example, had been no serious threat to the well being of their relationship. Janie also suffered from leprosy, and Peter suggested that she had probably contracted the disease from him. His eyes were saddened when he said that although he did not feel guilty about infecting her, he felt deeply sorry for her. Luckily, there were no hard feelings between him and Janie.

Peter and Janie had five children: two daughters and three boys. Only their last born was still unmarried. Their children were well established in their work and family lives. Peter and Jane were able to pass their religious beliefs on to their family members as all their children were in some way active in the church. One son was in the music ministry

and another was a minister of a church. Peter felt that they were reaping the fruits of their labour.

Peter and Janie have good relationships with all their children, as well as their children's husbands and wives. They are apparently good friends with their children. He ascribed his good relations with them to the fact that he was a sensitive and gentle person. He declared that he had always been like that. From a young age he had never been involved in fights with other people. However, he did not allow others to push him around. The fact that he had always been straightforward encouraged others to ask him for advice. He did not hesitate to discuss people's problems with them and to suggest solutions. But in so doing, Peter claimed that he was never presumptuous.

Peter elaborated on the fact that he was still very active. He talked about the church he had built in 1992. In 1998 he had to slow down as he developed red spots on his right foot, which eventually developed into a sore. As time passed, more ulcers developed. In 2000 he was treated at the Addington Hospital, and their explanation of the ulcers was that he had blood circulation problems. Later on, especially when he developed claw hands, their diagnosis changed to cellulitis. Although he paid a huge amount of money for the consultation and treatment, Peter only received antibiotics, which, for obvious reasons, had no effect. Early in 2002, he was referred to Crompton Hospital after developing ulcers on his hands. The specialist said that he was suffering from rheumatoid arthritis, and referred him to the King Edward Hospital. This diagnosis made sense to him as his mother had died of rheumatoid arthritis.

Dr M of the King Edward Hospital diagnosed leprosy. He gave Peter medication and referred him to the Prince Mshiyeni Hospital. During that time, Janie developed a patch and was also examined by Dr M, who told her that she had contracted the disease from Peter. According to Peter, even in this day and age, there are still difficulties in diagnosing leprosy.

For 35 years he travelled all over the country, doing evangelical work. He trusted that the Lord would help him to work again in 2003. He was approached by the executive body of his church to be a “father” to young ministers who find it difficult to cope under stressful circumstances. They even made arrangements that instead of travelling by car he would be given the opportunity to make use of air transport. Peter alleged that he feels fulfilled. He travels all over the country, ministering to people.

I said goodbye to him at the bottom of the steep steps, knowing that Peter would be able to climb them if he had to.



Image 6.1

The town of Harding where Peter grew up



Image 6.2

The view of Marian Heights from Peter's house



Image 6.3

The steps at Peter's house

My story of Peter's story continues as we have a close look at how the three SOC themes manifest in Peter's story. Other coping skills, not covered by the three SOC themes, are also highlighted.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was revealed in the following way in Peter's story: Peter showed frustration with the fact that, even in this day and age, people in the medical profession showed an **inability to diagnose leprosy**. Peter had struggled physically before he was finally diagnosed. It seemed that Peter was able to work towards a point of **acceptance** of leprosy as the **knowledge** that he had regarding rheumatoid arthritis "**prepared**" him. He was also able to **demystify** biblical leprosy. In his own words:

Janie found it more difficult to accept the diagnosis of rheumatoid arthritis. Four doctors told me that I don't have biblical leprosy. They also told me that once they treated me, I could live with leprosy.

Manageability

Peter managed the disease in the following way: He was able to manage the disease more effectively as **significant others** (his close family members) were the only people who knew that he had leprosy and he never experienced **stigmatisation** from them. More specifically, he had a **strong marriage** and he enjoyed the support of his wife. I asked him why he had not openly revealed his diagnosis. He alleged that it was a difficult situation with coloured people. In his own

words: “We have a problem with coloured people, they like to spread news. Just the name leprosy will harm the church.”

It was obvious that Peter anticipated that if the community were to know, the **voice of the community** would be negative. However, he claimed that he was not **negative**: “I had opportunities, and therefore I feel **positive** in my heart. Although my hands and feet are handicapped, I can **continue** with my life.”

Although Peter felt predominantly **encouraged**, he admitted to finding it difficult and **frustrating** at times to cope with the chronic nature of the disease. He confirmed his frustration:

*Before I had leprosy, I was **independent** and used to do everything. I did repairs, like brickwork and painting. When I was younger, there was also a time when I used to travel many kilometres on bicycle. When I struggle to fix things now, I tend to get a bit **frustrated**. Then I have to **humble** myself and ask younger men (my sons or men at the church) to help me.*

However, it was obvious that Peter did not regard himself as a **victim**. He made it clear, for instance, that there was no possibility that he would move out of his house and into an old age home. He would rather help himself around as far as he could, and he was grateful to people who had been prepared to help him to deal with practicalities at home.

Although Peter claimed that he had to accept old age, it appeared difficult for him to perceive himself as being old. Whether this tendency had a healthy psychological basis, for instance, pointing to emotional energy, or an unhealthy basis such as anxiety is unclear and perhaps not relevant here. The fact remains that Peter regarded himself as content. He elaborated:

*A while ago I spoke to a couple of ministers who asked me if I did not work too hard throughout my lifetime. They asked me whether I was coping with life and whether I'm **depressed**. Perhaps I have worked too hard, but I don't blame anybody, I don't need **sympathy**. And I'm not depressed, I told them that I know myself and my abilities well, and that I was able to identify and deal with my burdens and problems. Materially, I have everything I could wish for. The Lord worked in the heart of an American to make a big contribution to my church. That helped me a great deal.*

It was obvious that the single most important factor that had helped Peter to cope was his religion. Our whole interview was tainted by the fact that he perceived the reality of God as vital in his attempt to survive this disease. In his own words:

I don't see darkness. In the Lord, you don't see darkness. I'm supposed to tell other people about their future in the Lord. Outside the Lord, there is no future. As a Christian, you should put your hope in God. I depend on God; He will let me know when my work is done. He decided to keep me here until my work is over. As a Christian, you don't give up. If God sees you don't work, he will take you. Then you don't have an opportunity anymore to do something for him.

Once, a white woman, a missionary, spoke to him, reminding him that Job said that although the Lord had slain him, he (Job) would still trust the Lord. According to Peter, Job was in control and his end was glorious. He refused to become passive: for example, he prayed a lot (especially for those who were ill) and read the word of God. The fact that he was in the position to spend more time at home offered him more time to communicate with God. He believed that there was more depth in his prayer life because of the extra time he had had.

Meaningfulness

The theme of meaningfulness was revealed in the following way in Peter's story: Peter believed that, even though the devil was the creator of illnesses, the meaning of disease was that:

*Difficult times come for a Christian. God allows illness to make us **strong**. Like in Job's case, God allows misery and trials (materially, physically and spiritually), but he also came to give us life. He referred to the truth in scripture which stated that Paul asked God to help him with a problem. God said to Paul: My **grace** is sufficient for you.*

In an amazing way Peter had therefore managed to refrain from intense **blaming** (of the devil), by acknowledging personal gain from the disease. He admitted that God had allowed this trial (leprosy) to "slow him down". Peter noted that, after the great performance of Elijah on Mount Carmel, Elijah went down and rested. Peter had regrets about working too hard and he believed that God probably felt that he needed rest.

Peter's ability to **transcend** was obvious in his response when I asked him what advice he would give to people with leprosy. His advice was:

They should give their souls to God. Physical life is not important. You can die through sickness and disease. If you don't have the Lord in your heart, you lose your soul. You will be damned forever.

Peter derived great meaning in life from the spiritual work that he had done. In his own words:

I feel fulfilled. I have travelled all over, ministering to people. I have done something for the Lord. All my children are active in the church. I see the fruit of my labour.

He believed that, although he had achieved most of his life's goals, there was still some work that he had to do in the coming year. Peter claimed that the Lord had decided to keep him on earth until his purpose had been fulfilled. God would decide when his work on earth was done.

Peter wondered aloud about some **passive** people who, when facing trials, feel they cannot go to church. They cannot serve God and they prefer to sit. He looked me straight in the eye and stated, "I **never sit.**"

Related SOC themes

The following additional themes also emerged in the way in which Peter coped:

- **Transcendence** and an accompanying ability to be **generative**, in other words to be able to contribute to the well being of others. In his own words:
For 35 years I travelled all over the country, doing evangelical work. I trust the Lord that I will work next year. By the grace of God and people, I am the spiritual father of many ministers. I was approached to be a father for young ministers who were stressed out.
- Peter appeared to have the ability to see the **bigger picture** instead of being bogged down by the crippling reality of the disease.
- **The gift of a strong role-model** in the person of his mother. He described her in the following way:

*I saw perseverance in my mother. She was very **strong**. She **encouraged** me and told me to be strong. There are always things ahead that you don't know.*

- In the absence of a strong father figure, she also taught him to be **self-sufficient** and to **take on responsibilities**. For example, after his father fell ill, he started at the age of fifteen to work to support his mother financially. In later life, Peter took on the responsibility of developing himself into a strong leader within his own family. His wife and children derived great security from the way in which he performed his patriarchal responsibilities. He seemed to identify strongly with “the father” archetype. Not only did he believe in “The Strong Father”, he also aspired to be one. Although Peter claimed that he had never been a fighter, it was always important for him to be **self-assertive** and to protect his rights, as well as the rights of his family members.
- **An ability to avoid guilt.** In clinical practice it is often observed that guilt forms the basis of depression. Peter does not allow himself to feel guilty about the fact that his wife probably contracted the disease from him. He stated: “I don't feel guilty. There is nothing I can do.”

Conclusion

Peter's strength lay in the abundance of physical and emotional energy that he had, and in the fact that his faith in God empowered him to see a picture bigger than simply the crippling realities of his disease. Perhaps Peter might have looked at his hands and longed for the times when he had a strong grip on the handles of his bicycle or on his butcher's knife. But he probably also realised that grip is rather a matter of the heart than a matter of the hand. Regardless of his line of thought, Peter had the maturity to realise that it is time to let go, to “slow down”. He realised that it is time to rest, to have a Mount Carmel experience, to avoid climbing the steep steps carved out in the hill that

painted the background of his home. He had time to contain the energy within him that sometimes churned in his heart and mind like the water that swirled round his house after a storm. He believed that, by the grace of God, he was still able to work and could conquer any storm that came his way. Anything is possible. After all, in the Bible Peter had the faith to try and walk on water.

Participant G: Janie

Personal Data	
Participant:	Janie
Age:	64
Ethnicity:	Coloured
Marital status:	Married
Year of diagnosis:	2002
Age at diagnosis:	63

My story of Janie's story

Janie (a 64-year-old female) is married to Peter, participant F. After my interview with Peter, I had a cup of coffee in Janie's kitchen. She had a green panelite kitchenette set. When I was little, we had a yellow one in our kitchen, and I felt at home. In the heart of Janie's home, her story unfolded. She was born on 8 July 1938. She grew up in the Harding area and was the youngest of five children (one boy and four girls). She did not know her father, who had a farm in the Vryburg area, very well. Janie interrupted her story as her youngest daughter came in to (supposedly) get a glass of cold drink after being at college all day. Mother and daughter's eyes met, and their bond was tangible. Janie continued with her story, explaining that her mother, a housewife, died when she was very young. Her father remarried and lost contact with her (Janie). Her elder sister, J, took her in and she grew up with her. She regarded her brother-in-law as her father. She completed standard six, after which she left school and worked as a waitress until she married Peter at the age of 21. She has been a housewife ever since. In her spare time, she loves reading and visiting friends.

Her first symptoms developed when white spots appeared on her body. Fortunately, the disease was diagnosed in an early stage and therefore she did not suffer any

deformities. Doctor M diagnosed her and made the following remark, “You have your husband’s disease. Fifteen years from now when you are dead, I will diagnose it in your children.” Janie describes herself as sensitive, and such a remark was difficult “to swallow”. She loves people very much, especially her two good friends in the church. Like her husband, she is a committed Christian.

In my story of Janie’s story her unique way of coping is under the magnifying glass. Emphasis is placed on how the three SOC themes emerged in her story, but an open mind was kept in order to identify other related themes which do not necessarily form part of the SOC paradigm.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was revealed in the following way in Janie’s story:

Of everybody that I interviewed, Janie was (in my opinion) the most sensitive. As she connected with her reflections, thoughts and feelings of “then” and “now”, her eyes were constantly changing. Initially, I was almost afraid to ask personal questions, wary of stepping on hallowed ground. Janie was sensitive and therefore she was **disillusioned** after being diagnosed, and she construed leprosy as “a bad thing that happened to me.”

The diagnosis was clearly a terrible **shock** to her. She described her **confusion**, as she had not **expected** the diagnosis: “I felt as if the earth could open.”

Her immediate reaction was the fear of **isolation**. It was also very difficult for her when Peter was also diagnosed, since the image created in the Bible of lepers experiencing **rejection** was terrifying. Initially, she had felt that life was **unfair**, but she did not feel this way anymore. She did not perceive her future as being in **chaos** anymore. As a matter of fact, she stated: “I have **peace** now.”

Medical knowledge helped to give her peace of mind. After the doctors and specialists had told her that the disease was treatable and curable, Janie felt much better. She stated: “I told myself that it would make things worse to walk around with a sad face.”

She knew that things would work out as expected, since she was physically better. She grew towards a point of **acceptance** of the diagnosis of leprosy. Eventually she began to believe that there was **hope**, not **fear**, and that the diagnosis was not the end of the world.

Manageability

Janie managed the disease in the following way:

Her **belief in medical treatment**, and the fact that the symptoms subsided once she started using medication, **empowered** her. Eventually, she felt fine. Janie sensed that she was getting better, and that she was dealing effectively with the disease. She declared that her recovery was due to a **divine intervention**, and that God had made her and Peter **strong**. She no longer **focused** on the problem, but on the Lord. She alleged that she had grown as a Christian during the course of her disease and that her belief in God helped her a great deal in managing. She **accepted** that she could play an **active** role in handling the disease and claimed that she did not **focus** on the disease.

In my discussions with Janie it became clear that she and her husband were prominent and well-loved in their community. Yet, they were not prepared to test the loyalty of their community or the **social voice of society**, as, in their minds, the possibility of discrimination and disloyalty existed. The way in which the doctor announced her diagnosis also revealed the **harsh voice of society**, cutting like a hot knife through butter, hurting a sensitive soul deeply. We discussed the impact of society’s voice. She maintained: “People in our culture will not support us, they will isolate us. Our people are like that.”

Fortunately, Janie received strong **social support from significant others**. Peter and the children **encouraged** each other and her. The way in which they cared for her resembled her sister's care when Janie was young. Her sister's choice of taking the responsibility for her (Janie's) life, highlights once again the importance of the presence of one significant other in a child's emotional survival. Janie perceived Peter as playing a leading role in their relationship. She was, however, capable of **independent** behaviour. Initially in their relationship she was much more dependent on Peter, but when he began to show symptoms of leprosy as well she wanted to do everything for him. For example, he used to pay all the accounts. Nowadays, he would sit in the car while she performed that task. It became evident that the disease had become her **gift**, rather than just a **burden**. It showed her that she was able to function on her own. She alleged:

I will not fall flat when Peter dies, but it will be difficult. Even if he dies, there will be reason to exist. Our children should know that their mother and grandmother would always be there to comfort them.

There was a decline in sexual interest from Peter's side. Initially, it was difficult for Janie to adjust to this, but she **transcended** this problem by embarking on a process of **acceptance**, since she realised that he was ill and that nothing could be done about the problem. The phenomenon of **social comparison** was evident when Janie laughed, stating that: "Women are stronger in comparison to men when it comes to the handling of diseases. Men do not like to be sick, and they always think that they are stronger than women. "

Meaningfulness

Janie felt that for her the meaning of the disease lay in the fact that she had to believe that she could overcome the problem. In herself she witnessed **trust** and **growth**, and claimed: "I had to be able not to worry and to wonder what would happen next."

Although she did not know how she had contracted leprosy, she became aware of previously unknown strengths, and she was actually **empowered** by the disease: “At first I felt weak, and now I feel stronger than what I was.”

I asked her what advice she would give to other leprosy sufferers. The answer she gave reflected an element of “positive” **social comparison**. She said: “They should look at the problem and know that they can lead a normal life. I found it difficult to believe this before doctors told me so.”

Janie defined her ultimate goal in life as “To live for the Lord, my family and the church members.”

Janie was clear on what meaning a diagnosis of leprosy held for her. There were, however, other themes that emerged during the course of our discussion. A description follows.

Related SOC themes

The following additional themes emerged as significant in Janie’s attempt to cope with the disease:

The hardship of a significant other. Peter’s hardship prepared her in dealing with her disease. As she had great respect for her husband, the way in which he coped with the illness served as a perfect example.

She refrained from blaming anyone. She never blamed him for contracting the disease, nor did she **take out her negative feelings** on him.

Conclusion

With due respect to Janie's religious belief, the following saying from Zen Buddhism came to mind while I was interviewing Janie: "Before enlightenment, chopping wood and hauling water; after enlightenment, chopping wood and hauling water."

Janie might still continue washing her dishes; sweeping under the green kitchenette set and pouring her daughter a glass of cold drink after a hard day. But possibly with a difference, possibly with the realisation that those fortunate ones whose eyes are changing all the time, who are **burdened** to hear the last dying sounds in their souls, are not **paralysed**, but **empowered**.

Participant H: George

Personal Data	
Participant:	George
Age:	32
Ethnicity:	Zulu
Marital status:	Single
Year of diagnosis:	1999
Age at diagnosis:	29

My story of George's story

You see 'the Georges' at a distance, the 'Good type', the 'What-you-see-is-what-you-get' type. 'Gentle' George was born on 12 July 1970 in Durban. He was 32 years old when I met him. He grew up in Malawi (living there from 1975 when he was four years old, until 1994). His father died in 2000 at the age of 71 after an asthma attack. His mother died in 1996 at the age of 55. He had a younger sister, who was studying to become a secretary, and a brother, who was a lorry driver at the harbour. George lived with both his brother and sister in the township of Lamontville (near Durban). He had a good relationship with his girlfriend. He told me that he wanted to marry her and start a family, but he had to pay twelve cows (worth R3000 each) as lobola. Unfortunately, he did not have R36 000 to pay lobola.

George's parents did not want him to be exposed to the violence in Kwazulu-Natal when he was a child. As Malawi was a relatively crime free country during the time of George's childhood, his parents decided to send him and his brother there. They were looked after by his aunt and uncle, who was a farmer in a rural area. This couple also had two younger children (a boy and a girl). His aunt was a housewife and although she was strict, she made him feel safe. The fact that his aunt treated all the children equally

strengthened his relationship with his cousins. They lived in an informal settlement on a farm where they had to subsist on the farm produce. His aunt was a Christian and she took them to church regularly.

His parents and sister stayed in South Africa. He saw his parents only twice, his father at the age of seven, and his mother when he was fifteen. When George was 23, he saw his parents again. As his mother was an alcoholic they did not really have a good relationship. His father did not drink too much but argued a lot with his mother. George met his sister for the first time when he was 23. Initially, they did not get along very well as she was used to living alone with her parents. However, they sorted out all their problems and established a solid relationship.

George completed grade twelve and enrolled for an LLB at Unisa. I asked him why he wanted to become a lawyer. His response was that this type of work did not require physical strength. If he had not contracted the disease, he would have loved to have become a sportsman. However, he was determined to become a lawyer. Furthermore, he was employed as an interpreter at the Durban magistrate's court. He then talked about his love for soccer, reading and music. He is a churchgoer and also a member of the church choir. He enjoys mixing with other people and regards himself as an effective communicator.

In 1993, he noticed patches on his left arm and back. Blisters also appeared on his body. Someone suggested that he might possibly have contracted leprosy. He preferred to deny the possibility. Although he had received inoculations when he was a young boy to prevent leprosy, he did not receive proper leprosy treatment. As time went by, he had no doubts in his mind; he was sure that he had contracted the disease as the pictures of leprosy patients corresponded with his symptoms. The uncertainty was very difficult for him to handle. In 1999 he was diagnosed by Dr M, after being referred by Clarewood Hospital to the Prince Mshiyeni Hospital. He had no energy and experienced a lot of pain. He had sores on his body, his feet burned and he had a pink complexion.

Furthermore, he developed claw hands. Nonetheless, George believed that he had a role to play in shaping his destiny.

My story of George's story continues as we have a close look at how the three SOC themes manifest in George's story. Other coping skills, not covered by the three SOC components, are also highlighted.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was revealed in the following way in George's story: Despite his optimism, it was difficult for George to construe his situation as positive. He explained:

*There was much difficulty and **uncertainty** in the years before I was diagnosed. I was not sure of myself; I felt physically weak, and it was a painful experience. I was also weaker than the other boys.*

He felt that his **future was bleak**, particularly when he experienced **rejection** from others. He made this clear: "Without leprosy my future would be brighter."

George described a difficult time in his life when he was **stigmatised**:

At one stage, I had rough skin and pimples. People looked suspiciously at me and they were avoiding me. There was also a nursing sister who told me that I had leprosy, and that she did not want to touch me. These incidents were painful and I found it increasingly difficult to be patient with people who hurt my feelings.

However, despite the hurt that had been inflicted by these people, he was able to **forgive**, and told himself that he should be gentler with such people. Although he valued honesty very highly, he attempted not to hurt others and apologised when he did.

Looking at George intently, I realised that he was physically a very attractive young man and that it must therefore have been difficult for him to deal with the physical deformities caused by leprosy:

Sometimes I feel that I have less confidence (especially with women) because of the spots in my face. Before treatment it was worse, there was rough skin in my face. I feel more confident now that I look better physically. I suppose it's because I feel equal to other people. Leprosy does not make me unequal; leprosy discouraged me physically, but encourages me to compete mentally with other people.

It seemed that George felt that he had to **compensate** for his physical appearance. In George's case **social comparison** therefore had positive consequences, as it sparked an element of **self-enhancement** within him. The development in George was significant. He moved from a state of disbelief and **denial** to one of **acceptance** and developed an ability to **generate** energy to take up the gruelling task of working full time, studying and supplementing the financial shortfalls of three other people. He even took a taxi and travelled quite a distance to meet with the researcher. He also seemed to see a bright future as he smiled, explaining that he was goal-orientated: "I'm definitely going to pass my exams."

Manageability

George seemed to manage the disease in the following way:

At times it felt as though the leprosy symptoms would haunt him for the rest of his life, but generally his **positive** outlook on life made it possible for him to cope. In my conversation with George, it was obvious that although he experienced a feeling of **despair** at times, he had **perseverance** and tried to remain positive.

It's very difficult. Sometimes I tell myself it will be there until my death, but I'm positive. I'm still alive like other people; there are people with other diseases. Overall, I'm becoming more positive; most probably because I've regained my physical strength.

The phenomenon of **social comparison** surfaced in our discussion as he told himself that there were people suffering from other diseases who were coping well. He told me that he was still alive, “*like other people*”. What helped George to cope with the disease was his **acceptance** of the diagnosis. He was able to **embrace** the fact that God knew that he would contract this disease and also knew how long it would last. He explained:

It is God's will. God knew that we would be suffering and for how long. I would just surrender myself to God and have accepted the fact that I then have to carry this disease by the Lord's will.

George had to **transcend** the reality of managing practically with the disease over a long period of time. In order to cope, he **invested in God**. He believed that the answer lay in surrendering to God and abiding by God's plan for him. At the same time, he saw the disease as a challenge. He wanted to ensure that he explored **all treatment avenues** in order to control the disease. The fact that he was taking **medication** gave him a feeling of **control**. In his own words: “I have control, especially because I'm taking treatment.”

However, he would have loved to be completely free from leprosy; George was keeping **a dream alive**. Although he did not have children of his own, his brother and sister did not earn much and he supported them and his girlfriend financially. He explained:

My brother and sister earn little money. Therefore I have a responsibility to look after them as well. I want to work hard and get a living for my brother, sister and girlfriend as well. It is a challenge.

Although he allowed them to be financially **dependent**, he was financially completely **independent** and took up the challenge of providing for his own financial needs: “I depend on myself.”

He did not feel uncomfortable with this imbalance in their relationship or that he had to take most of the **responsibility**. In fact, he believed that it strengthened his relationship with them, especially with his sister. His independence and related self-sufficiency did not mean that he did not **connect** with, or for that matter, **belong** to people. He enjoyed **social support from significant others**, felt comforted by the love of family members and his girlfriend and by the fact that he had never experienced any **discrimination** in his inner circle. His girlfriend was not only emotionally but also practically supportive. She not only gave him positive feedback about his physical appearance, but also tried to limit the possibility of his harming himself. For example, she did not allow him to cook. Furthermore, George showed connectedness with the broad community. He told me that he was regularly visited by friends, workmates and fellow members of the church society.

Meaningfulness

In our discussion, it was clear that George gave meaning to the disease in the following way: He stated:

People deal with leprosy in different ways. Some people deal with it in a positive way, and others negatively. I did not handle the disease positively

in the beginning. Perhaps the biggest meaning of the disease was that, after being shy and afraid of discrimination, I became self-confident.

He was able to move from being afraid to **accepting** the disease. Right through our discussion it was evident that George was able to overcome his **insecurities** and that he had grown in **self-acceptance** and **self-confidence**.

Related SOC themes

The following additional themes regarding the ways in which George coped emerged:

Disclosure versus secrecy. Despite the emphasis that George placed on honesty, it was noticeable that he took **ownership** of “close to home” feelings. For instance, I asked him, as he had reduced sensation in his hands, whether this bothered him when he touched his girlfriend. His response was, “She does not know.” Not only had he decided not to reveal these intimate feelings, but he had also decided that it was not beneficial for everyone to know that he had the disease. He did not reveal his diagnosis to any person not belonging to his inner circle

To be goal-orientated. He confirmed: “I put high standards for myself. I still have dreams. I have not achieved much until now.” He wanted to work hard and earn a living for himself, as well as for his family. He admitted: “My family is holding me back.”

Regardless of this realisation, George was committed to his family and he expressed a deep sense of moral obligation to contribute to the wellbeing of others. George explained: “From time to time I motivate people, whom I suspect to have the disease, to come to the clinic.”

To have a social conscience which could probably (at least partly) be attributed to his **connectedness to his roots**; to the values that had been instilled by his rural environment and his strict/steady surrogate parents. It could be said, considering the psychosocial functioning of his biological parents, that he had been brought up in a more secure environment than his biological parents could have offered him. The lack of contact with his biological parents was perhaps beneficial in terms of his general sense of well-being, more especially as he did not construe the absence of his parents as abandonment but as purely due to circumstances. The presence of one person who really cares and develops the child holistically.

Whilst I was interviewing George, an analogy of young George came to mind. I saw him listening to the “teachings” of his uncle and aunt by candlelight, telling him to be honest, pointing to his moral obligation to be kind to his brother and sister one day, and to pay lobola as he put it: “Because it’s the right thing to do.”

Transcendence. The relief of being sure about the nature of the disease motivated George to advise people whom he suspected of having leprosy to go to the clinic.

Conclusion

We concluded our interview as George had to return to work. I acknowledged the fact that central Durban was far away, and I offered him taxi money. He smiled, “No thank you, I’m okay.” Perhaps it was worthwhile for George to have travelled the distance - perhaps he enjoyed having the opportunity to voice his story.

His old voice stating: “Leprosy? - it could not be.”

And his new voice: “It is there, and it’s fine.”

On his way to work in the morning, he might pass people making fires in “konkas”. He might feel the heat, never forgetting how leprosy burnt him. But he would also never forget how he had managed to keep his dreams alive. And perhaps the most vivid dreams are dreamt in an environment where people have time for each other, where there is still naivety unscarred by streetwise city life.

Participant I: Passion

Personal Data	
Participant:	Passion
Age:	41
Ethnicity:	Zulu
Marital status:	Married
Year of diagnosis:	1998
Age at diagnosis:	38

My story of Passion's story

Passion, an energetic 41-year-old man, was born on Christmas Day 1960 in the town of Bulwer, 174 kilometres from Durban. The town is surrounded by mountains which in wintertime are covered with snow. He described Bulwer as a very cold, quiet place with fresh open spaces. He grew up as the second eldest of four brothers and three sisters.

His father is a pensioner, living with his mother, who is close to 60 years old. Passion's mother was a housewife, but his father left them and she had to do "piece jobs" to make ends meet. Passion was about twelve years old when his father disappeared to Johannesburg. He described his father as being a strong and positive father figure initially, but because he had no schooling, the city was attractive. His father returned to them years later. Because he was worried about his father's well-being, Passion went to look for him when he was 25 years old. Passion described how, when his father saw him, he "was shaking". Acquaintances of Passion's father did not know that he had a grown son. His father said, "Just wait. I am on my way home."

Passion was not angry with his father because he had left them, but his mother was furious when his father returned. She remarked bitterly that the house that she was living in was

her property, and that her children had built the house for her. Passion reprimanded his parents, and demanded that they stop the fighting as they were both his parents. He told his mother not to talk behind his father's back. At times his father still disappeared for as long as two months. His father loved women and found it difficult to resist liquor. Passion was adamant that he would not leave his wife and children as his father had. He said: "No, I have a good brain. What I want to do, I must do in Bulwer. It is senseless to go to another town, not having money in your pocket."

As Passion did not have money for schooling, he completed only standard 8 and left school at the age of 15. When he was 16 he started working as a chef at Sani Pass Hotel (a hotel near the township where he lived). He has worked in restaurants in and around Durban ever since. He has no formal training as a chef but has learnt all he knows through in-service training. In his free time, his hobbies are playing soccer and watching television. Passion does not really have friends with whom he spends time. Sometimes he finds it difficult to trust people.

Passion contracted leprosy in 1998. The disease started with ulcers on his legs, spreading to the rest of his body. At that time, the manager of the restaurant said that he could not work with food if he had ulcers. Dr H (at the McCord Hospital) diagnosed leprosy and told him that he would have to take medication for five years. Passion's left hand became clawlike and lost all sensation. He found it difficult to grasp things and to perform tasks such as counting coins. Furthermore, he experienced a decline in sexual activity as he was (at times) unable to get an erection. Although Passion believed in God, he did not call himself a Christian.

Passion openly described his wife (with whom he has been happily married since 1987) and two daughters (aged thirteen and eleven). His wife worked in a restaurant in Pinetown. Another child, S, who was born out of wedlock, was also living with them. Proudly, he mentioned the fact that S did not like her mother and that she preferred to live with them. He described himself as a good man and said his children loved him.

Although he had a good marriage, his wife found it difficult to trust him because he had had so many girlfriends before they became involved. He told her that it did not have anything to do with her as he had not been in love with them. He admitted to me that he sometimes “jumps over the fence” (has extramarital affairs). During our interview, a woman colleague came in, touched Passion’s shoulder and referred to the fact that he was always laughing. On hearing this, Passion did not hesitate in living up to this reputation.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was revealed in the following way in Passion’s story: Passion’s **self knowledge** and an accompanying **belief in his ability to cope** were the “keys” he utilised to make sense of the disease. His belief in his ability to cope stemmed from a deep-seated perception that, as a leprosy sufferer, he had to exert **inner control** in order to cope. Passion maintained: “By having leprosy, I did not have one hundred percent control, but I feel in control.”

It was also evident from my conversation with Passion that he believed that this disease had not really influenced his **self image** in a negative way. There was no trace of uncertainty: “I feel good about myself. Once you have this disease, you need not to stick your mind to this disease. By sticking your mind to this disease, you will be unhappy.” Furthermore: “I am **strong**; no one opposes me.”

His belief that he usually had the “verbal upper hand” points possibly to self-confidence. Another probable indication of Passion’s healthy ego, is that he claimed that he had the ability not to **personalise** people’s questions and opinions. Passion’s ability to exert inner control was therefore not limited to the way in which he construed the disease but

also influenced the nature of his interactions with others. In my discussion with Passion I came to the realisation that he believed that instead of **fixating** on the negative side of the disease, **transcendence** was essential in order to fulfill a **societal responsibility**. He stated that by focusing one's mind on this disease, one "would become nasty towards other people."

Passion admitted that during the course of the disease he became short-tempered. However, he believed that he (and others) should have **patience**. For example, he once told a storeman: "You must not be so impatient, this grocery store is like a mamma, we need you."

He accepted the fact that some of his muscles were paralysed and would never regain their function. Although it saddened him, he knew that he had to **embrace** this reality and **focus on positive things**. He elaborated:

***Negativity** will not take my disability away. It helps me to know that the disease will stop. Some of my muscles won't work again; I'm not happy about that, but I accept it. I'm not managing properly as I have in the past (for example, counting coins), but I am not depressed, because I **understand my situation**.*

In contrast to most other participants, Passion's ability to be positive was not grounded in religion.

Manageability

I asked Passion what kind of advice he would give people suffering from leprosy. His response was that he would advise them to refrain from thinking interminably about the disease. Furthermore, they should **believe in medication** and use it consistently. He also added that they had to continue **leading a normal life**. Passion managed with the

disease by receiving **social support from significant others**. His “inner circle”, including his wife and immediate family, were all aware of the diagnosis but everyone **accepted** and never **rejected** him. He maintained: “I am a good man; I have a good marriage and my children love me. At night, my children are sleeping in my bed.”

Within his workplace there was complete **transparency**, and Passion did not see the value of **deception** about the disease. As colleagues were all aware of the diagnosis, it was common knowledge that he could not continue with his work as a chef. For example, they knew that because of the lack of sensation in his hands, he was unable to cook. The **harsh voice of society** is heard regularly, not hesitating to persecute leprosy sufferers and make them believe that ostracism is their only destiny. Surprisingly, Passion heard a **gentle voice of society** - he was given the job of supervisor of the chefs and cleaners as management did not want to lose him. Furthermore, people were more than willing to assist him with hard physical labour. Such acts of goodwill made him feel that life was not treating him **unfairly**. I was, however, convinced that there was much more in the equation than the kindness of society. All his white teeth were visible when he smiled broadly and added: “I am a friendly person, but I’m strong. No one opposes me; I have a way to talk.”

Passion proved to be not **passive** but consistently **active** and definitely not a **victim** of circumstances. He ascribed his work success partly to his zest for life and was impressed with the nickname that I had given him, “Umdladla”, the Zulu translation of the word “passion”.

Meaningfulness

For Passion, the meaning of contracting the disease lay in the fact that it gave him the opportunity to **reflect** on his values regarding friendship. He suggested that after contracting leprosy, he did **dissociate** a little from the community. He elaborated: “After

getting leprosy, I withdrew a bit, and that strengthened my family ties. It also helped me to distinguish good friends from the bad.”

That made his **association** with his family stronger and gave him the opportunity to regard his friends from a **distance**. Eventually he was in a position to discern between “good” and “bad” friends. The fact that he had been unfaithful to his wife and that he found it difficult to trust people did not seriously hamper his interpersonal relationships.

Related SOC themes

Passion coped well as:

- **Blaming** others was absent. Despite the fact that he believed that he had contracted the disease from someone, he did not exclude the possibility that someone might have given him *muti*, as he is the only person in his family to have the disease. However, he did not blame someone specific for having this disease, nor did he consciously turn negative feelings onto other people. He also forgave his father for abandoning him at the onset of adolescence when he needed someone to initiate him into manhood.
- **Connectedness** to “roots” seemed to be essential in his psychosocial functioning. Despite the fact that Passion was in midlife, he still perceived himself as a resident of Bulwer as his family was still living there. Although he had three brothers and sisters, it was Passion who went to look for his father. Despite his mother’s resistance, he cherished his relatedness with his father and was prepared to **forgive** his father. My observation was that Passion was almost intrigued by his father’s indulgence (alcohol and women) in order to cope with life. Regardless of the different value systems he and his father had, he showed compassion towards him. This was possibly a result of the fact that he had had to refine his value system at an early age without the presence of a father. Passion claimed that, from a very young age, he made an

effort to distinguish between right and wrong. The role of his mother in this issue was not highlighted by Passion.

- **He derived energy** from his interpersonal relationships. It was obvious that he loved people and that his relationships with, for example, his children and colleagues, generated energy within him.

Conclusion

A colleague once remarked that psychotherapy is “tainted with psychopathology”. In my conversation with Passion, I made the willful decision to allow him to talk freely; I refused to focus on possible problematic behaviour such as his lurking impulsivity. Instead, I valued his abundance of energy and was puzzled by how he generated it. Within the **opposing elements** of his personality lay the **maturity** of Passion’s personality; the fact that he had the ability to become emotional and fiery, but that he had made a conscious decision not to become entangled in the issues of others. His ability to draw boundaries with regard to his mother’s bitterness serves as an example of this. He preferred to **channel his energy** in other directions. This process does not imply insensitivity, but rather the maintenance of a healthy balance between association and dissociation.

Participant J: Jalo

Personal Data	
Participant:	Jalo
Age:	21
Ethnicity:	Zulu
Marital status:	Bachelor
Year of diagnosis:	1996
Age at diagnosis:	15

My story of Jalo's story

Jalo, an introverted 21-year-old man, was born on 23 March 1981. He grew up in Cato Manor and was still living there when I interviewed him. He described his village as a lovely and peaceful place. He was living with his mother (a cleaner at the Addington Hospital), an uncle and an adopted brother who was attending high school. His father, whom he had only met once (in 1998), lived in Stanger. Emotionally, he invested primarily in his mother and he was not used to having a father. He was a first year student in Sound Engineering at a technical college at the time of the interview. In his free time, he watched movies and played sport. He had a couple of friends with whom he played soccer, but bashfully remarked that he had no girlfriend.

In the middle of 1996, at the age of fifteen, he developed numerous nodules on his body. He had lesions all over his body, his hands felt strange and he lost his eyebrows. At that time, he did not even want to look at himself in the mirror. Although he was supported by friends, some acquaintances laughed at his facial deformities and that made him terribly sad. He had previously been taken to a witchdoctor by the uncle he was staying with. The witchdoctor did not help him at all. As in the case of so many of the leprosy sufferers I have spoken to, as I watched him leaving the room the sense of endurance, growth and victory he conveyed in an understated, introverted way was almost tangible.

My story of Jalo's story continues as we take a close look at how the three SOC themes manifest in his story. Other coping skills, not covered by the three SOC components, are also highlighted.

Emerging SOC themes

Comprehensibility

The theme of comprehensibility was manifested in Jalo in the following way:

Initially, I recall having my doubts in my interview as to whether Jalo should have been identified as a "coper". His introverted persona, his soft-spokenness and shyness were misconstrued as a lack of self-confidence. As our interview progressed, my reservations about Jalo were replaced by a perception that this young man was probably more able than most individuals in his peer group to make mind shifts regarding his disease, and to grow towards a point of a feeling of **empowerment**. But as with most leprosy patients, this was definitely not the feeling he had at the onset of the disease. Like to other patients, he experienced **confusion**. The fact that Jalo had not been diagnosed for a year evoked feelings of utter confusion and it was difficult for him to comprehend what was happening to him. He elaborated: "It was very painful and it felt like life was unfair, but now I have peace; I don't feel pain anymore. I always look forward, I never look back."

The severity of his symptoms must have been a complicating factor. While we were conversing, he accidentally saw a drawing in his medical file which indicated where he had nodules (Annexure 3). He showed amazement at the reality of the extensive nature of the symptoms he had presented long ago. This was a very painful period in his life. In his own words: "For a year, I did not know the diagnosis. When I was diagnosed at Prince Mshiyeni, they told me that I was going to be cured. Things are under control, but they weren't at that time."

Furthermore, medical **knowledge** had given him hope. When he was eventually diagnosed and informed that he could be cured, he was able to cherish **hope**. He maintained: "Life goes on. My mother encourages me; she tells me that I must focus. I am focused and one day I will have a good life with a house, wife and child."

However, even after being diagnosed it was at times difficult for Jalo to make sense of his condition. As in the case of other patients, he relied on personnel from the Leprosy Mission for **social support**. He expressed his negative feelings towards Sister E, the nursing sister of the Leprosy Mission, but he admitted that to a certain extent he always had a feeling of being "**free**". He explained:

People who talk to my friends laughed at me. Even when they were laughing at me, I was free; I had hope. I knew at the time of the onset of the disease that I would recover and that I would look the same like other people.

I asked him what the reason for this positive attitude might have been. As his response was that he knew a time would come when he would be "the **same** like other people" it was obvious that an element of "positive" **social comparison** was always present. He did not focus selectively on his physical condition and felt that the only way in which he differed from others was physically. As time went by, Jalo increasingly felt that everything was alright and that life would **continue**, notwithstanding the fact that he had contracted leprosy.

I showed him the pictures of the leprosy sufferers on the wall of the Mission's office, and asked him what advice he would have given them about coping with the disease. He said that he would talk about his own experiences, telling them what had happened to him, that he had looked like them before but that he had recovered. He would

encourage them and try to give them hope. He explained: “I will tell them that they must never go down, but rather believe that the disease can be cured”.

I felt that that was not all Jalo had experienced. Intuitively, I had the impression Jalo was also intrigued and impressed by the road he had travelled.

Manageability

Jalo was able to manage the disease in the following way:

The emotional and **social support from close family members** helped him to manage the disease. In his own words:

God has given me people to help me. I have a good life already; my mother supplies my needs. I don't have the support of my father, but I'm not angry with him. I am not used to have a father, my mother helps a lot.

In, and perhaps because of, the absence of his father his mother played a major role in the **process of acceptance**. In my discussion with Jalo, it was obvious that his mother was goal-orientated and that her encouragement was not **passive** pity but **active** encouragement (encouraging him to pull himself up by his bootstraps). He claimed that she encouraged him all the time, telling him to **focus** and to work towards a goal. He defined himself as being focused and working towards the **goal of having a good life** with a wife and children and a comfortable house. He was **certain** that one day he would realise this goal. As a matter of fact, he stated that he was already experiencing something of the good life that was awaiting him. Given the reality that his mother was supplying most of his material needs, I wondered whether his **dependency** also had an emotional dimension. He denied emotional dependency and claimed: “Even if my mother was no longer there, I would be able to stay focused. If you are dependent on someone else, you will fall flat if that person goes away.”

He maintained that he would be able to remember everything she had told him and taught him throughout his life. It was obvious therefore that he had faith in the **instilled values** that he had acquired from her.

In contrast to some other patients, Jalo received **social support from significant others** who were not biologically related to him. For example, his neighbour (a woman), took him to doctors in Stanger. He elaborated: “When I did not want to look at myself in the mirror, I told her about the way I felt. She did not reject me, she supported me.”

He also told his educator about these feelings. In his own words: “She encouraged me to continue with studies after school. At a time, I was negative, but I told myself not to lose hope. My goal was to become a medical doctor. But I did not get selected.”

It was clear that Jalo attributed his ability to cope partly to a **divine intervention** as God had given him many true friends who supported and respected him. He stated: “My friends also continue to support me. We respect and help each other.”

In a reciprocal way, Jalo and his friends helped one another. He found it bearable to live with leprosy mainly because people **accepted** and did not **reject** him.

Apart from the support that Jalo received from close-knit family and significant others, his other pillar of support was his **belief in medication**. Whenever he felt that the situation was hopeless, he was reminded of the fact that medication would solve the problem.

Meaningfulness

Jalo gave expression to the meaning of leprosy in the following way:

To have felt in control and to have been able to win the struggle against the disease seemed to be the most significant value that Jalo derived from contracting the disease. Jalo progressed from a **state of hopelessness** to a state of feeling **in control**. When he had started developing leprosy symptoms, Jalo felt that things were not under control. He stated: "Things are under control, but they weren't at that time."

From our discussion it became clear that Jalo was no longer experiencing the emotional pain which he had initially suffered. He said: "I have **peace** now."

He believed that a leprosy sufferer should not hesitate to **fight** the disease. In his own words: "Sometimes you lose hope during the course of this disease. You must fight this disease. Leprosy helped me to fight. If I get this disease (nodules) again, I will fight it."

Jalo contracted this disease as a teenager and the visible signs on his face (the presence of macules and nodules) were damaging. Initially he did not feel confident enough to visit friends or to play soccer. However, during our interview, he maintained that he no longer experienced any lack of **self-confidence** and even described himself as being attractive. He said: "I don't have self-confidence problems now because of leprosy. If I had not been **strong**, I would not have been able to come for an interview."

Another sign of his **empowerment** was that Jalo expressed no doubt in his ability to succeed in his studies. He preferred to **concentrate on the future**. In his own words: "I always look forward, I never look back."

He described himself as having the physical and moral strength to withstand the disease. He stated that he was **positive** and even if he developed symptoms (nodules) again, he would "fight the disease."

Related SOC themes

The following additional themes emerged as being significant in Jalo's attempt to cope with the disease:

He coped well due to the following:

- **Blaming** others had never been in the equation. He did not know how he had contracted the disease and did not blame any person for having the disease. However, there seemed to be some blame on a supernatural level: "Maybe the devil gave it to me". He was not angry with his uncle who had taken him to the witchdoctor who had not helped him at all, as he knew that his uncle was only trying to help him. Although Jalo did not blame the witchdoctor, he had no faith in the expertise of the traditional healer. He also never projected his painful feelings onto anyone. Furthermore, Jalo stated (softly) that he was not angry with his father for leaving them.
- He **transcended** his feelings of vulnerability. While he was still attending school, he had the dream of becoming a medical doctor, but unfortunately he was not selected.

Conclusion

Perhaps Jalo's primary coping strategy is revealed in his advice to others not to give up hope. It was probably possible for him to be hopeful as he had the strong support of his mother who motivated him and instilled in him the value of perseverance. A sense of pride in the way he had "fought back" served as a basis for his conquering any possible future distress.

CHAPTER 7

SYNCHRONISING THE INTERFACES: A COMPARATIVE ANALYSIS

INTRODUCTION

In the previous chapter, the way in which the three SOC components of comprehensibility, manageability and meaningfulness manifested themselves in the participants' stories, was described. Emerging themes that might relate to other salutogenic constructs were also identified. The unique as well as the shared ways of coping will be discussed in this chapter. In the kaleidoscope of stories, each person's story retained its own colourful nature, but an attempt has been made to synchronise the interfaces; to create an integrated picture. In order for the data to have primacy, the researcher did not limit information to the three SOC categories, but identified ten common themes that describe the shared and unique ways in which the participants cope with leprosy. These shared themes are discussed below.

CONFUSION VERSUS HOPE

The participants' stories revealed how initial shock, confusion and lack of control, gradually made room for enlightenment and the need to manage and control – eventually igniting hope.

Although the participants experienced a variety of emotions immediately after the diagnosis of the illness, it appears they were utterly confused and felt out of control. These emotional reactions to leprosy correlate with the study by Scott (2000) on the psychosocial needs of leprosy patients. A few examples from the participants' stories to highlight these issues follow.

Grace was shocked, negative and disillusioned and she refused to accept the disease. She felt life was unfair. Busi was confused, uncertain, upset, sad and unsure about what leprosy was all about. She felt humiliated by the neighbours who laughed at her and Amatikulu Hospital, which was fenced like a prison, made her feel anxious. In chapter three it was indicated that children with leprosy experience anxiety from being segregated and apply ego defence mechanisms to cope with their illness. It was also suggested that they seem to have shaky egos and lack independence in feeling, thinking and action (Chauhan & Dhar, 1980). Initially, Sara was upset and fearful - especially because of the biblical image of leprosy. Mali was unable to understand what the disease meant and the physical pain was very difficult to deal with. Ziqie was heartsore and angry. It was confusing for her to be uncertain about the disease. She felt rejected, exposed and humiliated when the schoolmaster chased her away. Peter felt frustrated as people in the medical profession were unable to diagnose leprosy. Janie feared isolation and was shocked and disillusioned as she had not expected the diagnosis. Initially, George was negative as he was rejected by people. Incidents of stigmatisation were intensely painful. George found it difficult to cope with the chronic nature of the disease. He applied a defence mechanism of compensation for his physical appearance, by developing his intellectual abilities. As it took a year for Jalo to be diagnosed, it was difficult for him to comprehend what was happening. He experienced confusion and sadness when some acquaintances laughed at his facial deformities. In a South African study by Scott (2000), eleven (of thirty) participants contemplated suicide; six of these were male. However, in the present study, all the participants confirmed that the possibility of committing suicide was never in the equation.

The initial sense of confusion among the participants was eventually combated with a need for control. The participants were determined to take charge of the disease and their lives and would not allow the disease to control their lives. As was revealed in the stories of the participants, they all showed elements of the sense of manageability. According to Antonovsky (1987c; 1996b), a person with a strong sense of **manageability** will believe that resources to cope are available, and will not feel

victimised by events. He or she will be less likely to deny them or to dissolve under their weight and, according to Levenstein (1994), more likely to maintain health by avoiding self-destructive activities such as substance use, and more likely to maintain health by creating and executing efficient plans of action. Apparently, none of the participants abused substances.

In addition Antonovsky (1987c) highlighted the fact that the stimuli or challenges with which a person is confronted are not always desirable. Death, war and failure could be involved, but the person high on **comprehensibility** understands the challenges and makes cognitive sense of them. In this way enlightenment around the issue occurs. Frankl (1984) also maintained that emotion, which is suffering, ceases to be suffering as soon as we form a clear and precise picture of what it is that we are dealing with. After the initial shock and confusion when diagnosed, a sense of manageability and comprehensibility clearly emerged from the participants' stories. Practical examples of how participants perceived themselves and how they comprehended their disease and their situation follow.

Grace knew that she had to go "through the channel". She made a conscious decision to accept the disease and she claimed that she always had hope. Busi was positive, self-reliant and believed that she had the ability to accept the disease. She believed that not everything was out of control. Sara no longer feared leprosy as she did not have the same idea about it as the Bible. She was self-confident and positive about life and believed that the disease had given her an open mind as she knew she just had to be patient and accept the disease. Mali stated that she had no choice but to accept that God had given her leprosy. She also believed that she felt much better as God touched her. Zigie and Jalo had hope and knew that God would help them. Zigie declared that she had always experienced some sort of control. Her path to understanding leprosy was, however, a process. Janie and Peter accepted the diagnosis and felt hope, not fear. George knew he had to accept the disease. He was able to embrace the fact that God knew that he would contract this disease. Although Passion felt that by having

leprosy he had lost complete control, he still had control in terms of the way he perceived himself. Passion and Jalo believed that they had to have patience as acceptance of the disease was a process. When Jalo was diagnosed and told that he would be cured, he told himself not to lose hope. Hope was therefore an active theme. Hollis (1993) suggested that: "Hope is based on what might be. Knowledge is the valued lesson of experience. Wisdom is always humbling, never inflationary" (p. 22).

But perhaps hope is grounded by the way in which you conceptualise the disease. It appears that, generally speaking, the participants were able to regain control as they were prepared to embrace the reality of the disease by accepting it. In Grace's own words: "Once you have accepted the disease, you find peace in yourself, and that leads to healing."

Viktor Frankl (1984, p. 137) stresses the importance of acceptance in the following statement: "There are situations in which one is cut off from the opportunity to do one's work or to enjoy one's life; but what never can be ruled out is the unavailability of suffering".

According to Kubler-Ross (1969), "acceptance" is the stage at which sufferers come to terms with their losses and find new purpose and **meaning** in their new circumstances. However, it should be noted that 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). Early acceptance may force the people to surrender all hope, leaving them 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 (Viviers, 2005).

Whether the participants were able to form a picture and cope owing to their genetic make up (nature), or to strengths that had been developed in their environment (nurture)

will probably always remain unanswered. However, Frankl (1984) suggests that, in exploring the meaning of life through suffering, freedom of choice seems to be of vital importance. To be able to choose his or her response in traumatic and adverse circumstances will empower the sufferer. The participants chose to take control of the disease and their circumstances. They had the ability to internalise the control process. This ability relates to Rotter's (1975) concept of locus of control as discussed in chapter four. This construct reflects the degree to which individuals believe they have control over events in their lives (internal locus of control) versus the degree to which they believe they are victims of fate, external circumstances and/or forces (external locus of control). It was obvious that the participants were able to exert inner control, and prevent significant control by people, external circumstances or their external environment. For example, to be confronted by mentally disabled people functioning in a different way, did not upset Grace. Busi did not turn any negative feelings upon other people or objects. Passion prefers to channel his energy in other directions rather than, for example, becoming enmeshed in the issues of others. Passion believed that he was strong and also that he did not personalise people's questions and opinions. He therefore reflected the ability *to draw emotional boundaries* between people. Bertine (1992) suggests that to grow up psychologically, it is absolutely necessary to find one's own boundaries, to choose actions from a unique personal centre rather than parrot someone else or echo collective opinion.

IGNORANCE VERSUS KNOWLEDGE

'Ignorance versus Knowledge' is a theme which is closely linked and in some ways overlaps with the previous theme of 'Confusion versus Hope'.

In her study on patients with different chronic illnesses Viviers (2005) suggested that all the participants gained mastery and control through knowledge. They sought knowledge from various sources to gain insight into their respective illnesses. In acquiring knowledge on their diseases and the treatment thereof, they gained control. The

knowledge gained may empower the patient to make informed choices about treatment options and how to continue his life with a chronic illness. Having the ability to choose his own destiny may create a sense of control for the patient. He is thus no longer a "victim" of the illness or the health care system, but an active participant in his treatment. From this perspective, knowledge is regarded as power and how power is constructed within the relationship between the patient and medical professionals is therefore important.

The stories of the participants in this study on leprosy also reflected the role of knowledge in their quest to gain control of their illnesses. The knowledge gained empowered them to make their choices on how to live with their illnesses. The fact that Grace was in the nursing profession, helped her to get distance from her culture and to be more objective about the disease. Grace had lived through ideas about the origin and consequences of leprosy. Sara had been given a book on leprosy by the sister of the Leprosy Mission. After reading this book, her fear vanished and eventually her ideas about leprosy changed from the daunting images in the Bible. She believes that she survived this disease because she regularly visited a nursing sister who taught her the necessary precautionary measures. The collective feeling amongst the participants was that the Leprosy Mission had been a crucial resource in providing emotional support and medical facts.

In the case of Peter, the earlier (wrong) diagnosis of rheumatoid arthritis "prepared" him and he felt that he thoroughly understood the nature of the disease. He gained a sense of peace in his belief that medical experts took care of him. Another contributing factor to Peter's feeling of control was the fact that the biblical images of leprosy had been demystified. Janie had been terrified by the image created in the Bible of people being ostracised. She had an intense fear of isolation. However, after the doctors and specialists had told her that the disease was curable and treatable, she felt much better.

From the very start, Grace had a firm belief in the prescribed medical treatment. When Sara and Janie started to use medication and the symptoms subsided, they did not fear leprosy any more. The medical treatment that Mali received from medical personnel at Amatikulu Hospital helped her to cope with the disease. Medication also helped Busi, Zigie, George and Jalo to feel in control. Passion's advice to people who had to cope with leprosy would be to take medication. Whenever he felt that the situation was hopeless, he concentrated on the fact that medication would solve the problem.

A complicating factor was that some of the participants were undiagnosed or misdiagnosed for long periods. Although doctors specialising in leprosy had consulted Grace, she tested negatively for a period of three years and was only diagnosed in 1997. Zigie was exposed to severe stigmatisation before she was finally diagnosed. Peter was upset by the fact that even in this day and age there still seemed to be difficulties in diagnosing leprosy as even a specialist was unable to do so. Jalo had not been diagnosed with leprosy for a year. This might have sown a seed of distrust in the medical profession which is a threat to participants using the medical profession as a resource to cope with the disease, and could have contributed to the lack of effective treatment that was sometimes reported by the patients. However, in this study it is clear that medical treatment contributed hugely to the participants' ability to cope with leprosy.

BLAMING VERSUS TAKING RESPONSIBILITY

Scott Peck (1990) maintained that whether or not a person progresses in therapy is a direct function of one's ability to take responsibility for choices and to cease blaming others or expecting rescue from them. It appears that the participants' ability to cope with the disease and their ability to grow emotionally could be attributed partly to their ability to take responsibility for their lives.

Busi and Janie refrained from blaming their grandmother and spouse for contracting the disease, nor did they turn their anger upon them. Despite the fact that Passion contracted the disease from someone, he did not blame others.

Neither Sara, Peter nor Ziqie blamed someone else. For example, Ziqie felt that she did not have any reason to blame anyone for having contracted the disease. Although Mali believed that God had given her leprosy, she did not blame Him. Jalo partly blamed “someone” by suggesting that the devil might have given them leprosy. However, if something or someone should be blamed, perhaps the devil is the ideal figure, as he is generally believed to be the carrier of darkness. Estes (1995) states that the devil symbolises the dark force of the psyche, the predator. The devil is an archetypal bandit who “needs”, “wants” and “sucks light”. Theoretically speaking, if he were given light – that is, a life with the possibility of love and creativity – then the devil would no longer be the devil.

Furthermore, the participants were forgiving and did not dwell on the mistakes of others. For example, Grace stated that she was not angry with the doctors. Sara was not angry with her three sons who did not assist her financially. George had peace, and he was able to forgive those people who stigmatised him. Passion and Jalo forgave their fathers for abandoning them. This synchronises with the statement of Jung regarding the role of parents (in Stevens, 1999):

Yet, as children we expect them (parents) to be gods, and it comes to all of us as a painful disappointment when we discover them to be fallible, like everyone else. As Oscar Wilde put it: Children begin by loving their parents; as they grow older they judge them; sometimes they forgive them (p. 122).

DISTANCE VERSUS CLOSENESS

Most of the participants experienced blatant stigmatisation, which created a distance with people whom they had intimate and non-intimate relationship. Some important people (relatives and people in the community) in Grace's life stigmatised her, basing their reactions on passages in the Bible. Some important people in her life were (after eight years) still very afraid of leprosy to make contact with her. Busi's mother was not allowed to touch her – not even when her father died - or to give her a food parcel and she was treated insensitively by nursing personnel. Sara's employers were not happy that she had ulcers, and eventually she lost her job. In her first year at school, Zigie fell ill and the principal chased her away. She and Janie were insensitively treated by medical doctors. A distance was created between these people as they heard harsh, condemning and rejecting social voices. When George had rough skin and pimples, people looked at him suspiciously, avoiding him. A nursing sister even told him once that she did not want to touch him.

Estes (1995) suggests that, while psychology emphasises the familial causes of anxiety in humans, the cultural component carries as much weight, for culture is the family of the family. If the family of the family has various sicknesses, then all families within that culture will have to struggle with the same malaises. She states that there is a saying "cultura cura", culture cures. If the culture is a healer, the families learn how to heal; they will struggle less.

Grace, Busi, Mali and Zigie had all been hospitalised during the course of the disease. This implied distance from their support system. As substantiated by Scott (2000), it seems as if they first relied on traditional measures to address the disease. However, whilst cultural beliefs sometimes provide comfort to people, Grace felt that her cultural environment did not advantage or disadvantage her in any particular way. Like Grace, Sara distanced her from her cultural beliefs as she showed distrust in traditional healing methods. A medical doctor even advised Zigie to consult a witchdoctor. Jalo

was taken to a witchdoctor by the uncle he was living with, but he felt that the witch doctor did not help him at all, and he felt negative about the experience.

In contrast to Grace's distance from her culture, she experienced closeness with medical staff and former colleagues from whom she received emotional support. Sara was diagnosed by a sister from the Leprosy Mission who comforted her and assisted her in coping with the disease. She showed strong resistance towards the cultural way of handling the disease.

There are also other examples of distance and closeness existed side by side. Busi received social support from friends, especially those whom she met at Amatikulu Hospital and who also had leprosy. Most of the participants declared that they enjoyed having social contact and to experience the closeness with friends. Jalo, for example, experienced the goodwill of his neighbour and teacher. Peter was supported by ministers. Where abandonment by close family members (for example, in Grace's case) occurred, these family members were replaced by "substitute supporters", for example, Grace's minister. Estes (1995) refers to this phenomenon by using the analogy of The Ugly Duckling; you may not belong to your original family at all. You may match your family genetically, but temperamentally you belong to another group of people (p. 166).

It was obvious that the quality of support by non-family members could not be remotely compared to the support offered by partners or close family members. Contrary to findings by Awofeso (1995) and Raju and Reddy (1995), that the divorce rate among the leprosy-affected is relatively high, none of participants in this study was deserted by their partners due to their diagnosis.

Busi had a good relationship with Buthe. Sara loved Tom and he was the main source of support throughout the course of the disease. Sara and Mali's partners did not want to leave them because of leprosy. Despite a decline in sexual activity, Passion and Peter

had good marriages. Their partners' compassion and their strong egos might have been their saving grace. Monick (1991) substantiates this:

Phallos, therefore, need not always require concrete phallus, however necessary phallos is as the basic image. If the inner phallic nature of the man is intact and hungry, his personality and his entire body become phallos. Celibate men who are constitutionally phallic are genuinely masculine (p. 18).

Peter and Janie had been happily married for the past 43 years and shared a mutual understanding regarding their sexual problem. They encouraged each other a great deal during the course of the disease. George had a well-developed relationship with his partner and she helped him with practicalities like cooking. GRRs (Generalised Resistance Resources) were described in chapter four as any properties of a collective or a situation which facilitate successful coping with the inherent stressors of human existence (Antonovsky, 1996a). A partner who is willing to walk alongside a leprosy sufferer, encouraging him or her and helping practically, could be described as an effective GRR.

Grace, Peter, Janie and Passion were outspoken about their well developed relationships with their children. It seems as if these relationships were essential in coping with leprosy. Busi, Zigie and Passion believed that significant others, some members of their families of origin, helped them significantly in managing the disease by not rejecting them and by being strong when dealing with the community. This result is contrary to the high incidence of rejection of leprosy sufferers by family members due to fear of contagion reported by Antony and Broota (1991).

Many of the (current) social responses to people with leprosy are based on biblical teachings (Tare, 1991). Despite this given fact, some participants (surprisingly) heard gentle voices in the society. Passion was given a supervisory job and people were

willing to help him with physical tasks. Peter was also assisted with practical work and a source of inspiration to Jalo was his teacher who encouraged him to continue with his studies after school.

But perhaps most remarkable was participants' closeness to themselves. Ziqie, for example, had an ability to make contact with her feelings whether those feelings were negative or positive. Leprosy gave Passion the opportunity to reflect on his values regarding friendship. This is in sharp contrast to the tendency of some leprosy sufferers 'to latch onto others' in order to cope. Nietzsche (in Hollis, 1993) wrote a hundred years ago, "When we are alone and quiet we are afraid that something will be whispered in our ear, and so we hate the silence and drug ourselves with social life" (p. 101). This did not seem to be the case with most of the participants.

TO CONCEAL VERSUS TO REVEAL

Generally speaking, participants' immediate reactions were not to reveal the diagnosis. As time went by, some participants became more open about the diagnosis, whereas others preferred to maintain secrecy. When Busi was taken to hospital, the diagnosis of her disease was kept a secret. The secrecy made her feel free, and gave her an opportunity to adjust to the reality of the disease without being exposed to possible stigmatisation. Some participants preferred to retain complete secrecy about their disease. Sara believed that once you tell people that you have the disease, they send you to a sangoma who indulges in harmful therapeutic methods. Peter and Janie were convinced that if the community knew, its voice would be negative. Besides people in his inner circle, others did not really know that George had the disease. He was too afraid that people from the community would discriminate against him. In contrast, all Passion's colleagues were aware of the diagnosis. This could probably be attributed to the fact that Passion had a charismatic personality and was well-liked. He therefore felt secure in his relationships with his colleagues which made it easier for him to be open about his diagnosis.

PASSIVITY VERSUS ACTIVITY

Despite the image of passivity that is created in some literature about leprosy patients, it seemed to the researcher that the participants were (generally speaking) very active, also in their free time. They read the Bible and newspapers, were active in the church, visited people and played sport. Busi had faith in her entrepreneurial skills and was goal-orientated. She believed that she was supposed to rather focus on her aim of having a good home and a good life with her children, than on leprosy. She learned that from her parents. Busi and Ziqie were active in their entrepreneurial work. Zigie even established a disability group to discuss ways and means of earning money with other disabled people. Three participants (Busi, Mali and Ziqie) who had been institutionalised before, applied skills acquired in the training offered by the Leprosy Mission, Clarewood Hospital and Kwazulu Technical College. This is in sharp contrast to the findings discussed in chapter three of this study. Tare (1991) conducted a study in respect of patients discharged from two supposedly ideal rehabilitation centres and reported the sad revelation that the majority of trained-and-discharged patients were not continuing the trade-craft in which the training was provided and had become either beggars or agricultural labourers. Due to the fact that the participants are, generally speaking, not highly educated (See Table 1), they have to rely on other skills.

Zigie decided to put the past behind her and to go forward rather than down. Sara was also goal-orientated and believed that she was meant to make sure that she had good things and that her children led good lives. Mali made practical plans to survive, for example, she would sell oranges to buy tea. Janie claimed that she could play an active role in handling the disease and by focusing on her ultimate life goal, namely to live for the Lord, her family and the church members. Although Peter was retired, he was still very actively involved in church activities. Peter did not perceive himself as being a victim. He failed to understand how some passive people who, when facing trial, felt they could not attend church. He stated, "I never sit." George was goal-orientated as he believed that he still had much to achieve. He proved to be consistently active and

definitely not a victim of circumstances. Jalo felt comforted by his mother who gave not passive pity but active encouragement. Jalo defined himself as being focused and working towards the goal of having a good life.

Table 1: Education levels of Participants	
Participant	Education Level
Grace	JC 1, 2 and 3
Busi	Standard Eight (Grade 10)
Sara	Standard Eight (Form 2)
Mali	Standard Four (Grade 6)
Ziqie	None
Peter	Standard Six (Grade 8)
Janie	Standard Six (Grade 8)
George	Matric and Enrolled for LLB
Passion	Standard Eight (Grade 10)
Jalo	Matric and First-Year Sound Engineering

As discussed in chapter three, Pincus (1994) points to Antonovsky's work, which suggests that a strong sense of coherence, a measure of health within, may overcome an unfavourable and unfair social milieu, including unemployment and hunger. Despite the high rate of unemployment in South Africa and the low educational level of participants, it was obvious that they were active in creating opportunities.

None of the participants indicated serious financial difficulties: financially, they were self-sufficient. In fact, Busi, Sara, Mali, Peter and Janie were outspokenly proud of their

“nice” houses. Ziqie indicated that she worked hard to earn, for example, a cell phone. Although they did not overvalue material possessions, it gave them a sense of achievement and dignity. The researcher is reminded of the words of Jung in Hollis (1993 p. 140);

I have frequently seen people become neurotic when they content themselves with inadequate or wrong answers to the questions of life. They seek position, marriage, reputation, outward success or money, and remain unhappy and neurotic even when they have attained what they were seeking. Such people are usually confined within too narrow a spiritual horizon. Their life has not sufficient content, sufficient meaning.

The participants in this story definitely do not fit this description and rather displayed admirable fortitude and inner strength.

WEAKNESS VERSUS STRENGTH

Contrary to the reported tendency of many leprosy sufferers to slip into a ‘weak mold’. The strength of the participants in this study was tangible during the interviews. They were people who fought back. Although Grace was suffering from chronic eye discomfort – which was evident during the interview - she persevered and answered the questions, smiling frequently. Peter found it difficult to blink. His eyes became teary, but he persevered with the interview despite the discomfort.

If one has a close look at the physical agony leprosy sufferers are exposed to at various points in time (See Table 2), one can conclude that they revealed an extraordinary ability to cope. This is the very kind of strength that motivated Antonovsky (1987c) to formulate the salutogenic model and to therefore focus on strengths rather than pathology.

Table 2: Physical Condition

Participant	Description
Grace	Claw hands; lost one finger and another digit damaged; left leg amputated; right foot dropped.
Busi	Claw hands; nose collapsed; toe of left foot amputated. Loss of sensation caused serious damage to her hands as she constantly burnt them.
Sara	Hands looked peculiar.
Mali	Claw hands; right leg amputated. Only one toe on left foot.
Ziqie	Hands scarred, as well as clawed. Toes clawed.
Peter	Claw hands; inability to blink.
Janie	Patches on her body.
George	Patches on his left arm and back. Blisters appeared on his body. Feet burned, and a pink complexion. Rough skin and pimples. Claw hands.
Passion	Ulcers all over his body. Left hand: claw-like and without sensation. Some muscles permanently paralysed.
Jalo	Lesions all over his body; hands felt funny; lost his eyebrows.

The participants had to be strong in coping with this disease during its various developmental stages. Although it cannot be easy to deal with leprosy during any life stage, the resilience that some of these participants showed during their childhood is amazing. It was significant that, apart from the agony of leprosy that some of them had suffered as children, a significant number of them had been exposed to an unfavourable (and in some cases, abusive) environment at the onset of their lives.

When Grace was born, a doctor told her mother that she did not have much of a chance to live. Her father drank heavily, abused her mother and when she was ten years old, she had to go and live with her grandmother as her mother had to leave her to work in another town. Busi's parents were alive, but she lived with her grandmother (a leprosy sufferer). Her two younger brothers and a sister also had leprosy. The way in which Busi was stigmatised has been discussed earlier. Fortunately, her father and mother were loyal to each other and cared deeply for her. As Sara's mother worked as a domestic worker in Ladysmith, she was raised by her sisters and grandmother. They set a good example of how to look after children. Sara was nine months old when her father died of ill health. Mali's father (a farmer), and mother (a housewife) died when she was very small, and therefore she did not know them at all. Her two older sisters raised her. When Ziqie was still very young, her father disappeared to live with a young women in Johannesburg. Although she found this very painful, she had a strong bond with her mother. Peter's father drank too much, but they never experienced any serious familial problems. All his life, he had a good relationship with both his parents. His mother was a perfect example of how to be strong and served as a role model for Peter. Janie's father was not well known to her. After her mother died when she was very young, he remarried and lost contact with her. She grew up with her elder sister and her (the sister's) husband. Her brother-in-law was like a father to her. George had hardly any contact with his parents and did not have a good relationship with them. His father was negative and argued a lot. His mother was an alcoholic. George's uncle and aunt provided him with emotional security and a stable childhood. Passion was about twelve

years of age when his father left for Johannesburg. His father loved women and alcohol. Jalo met his father only once.

The presence of positive mothers and the physical absence of participants' unfit fathers are therefore significant. Wallot (in Corneau, 1991) noted that four times as many men suffer from alcoholism as do women; they also outnumber women (3:1) in the areas of suicide and high risk behaviour. In addition, men are more prone to schizophrenia than women. Wallot (in Corneau, 1991) concludes that the frequent absence of the father or of masculine models for young male children seems to explain certain behavioural difficulties connected with men's affirmation of their sexual identity. Fathers becoming emotionally present for their sons and daughters seems to be one of the few possible solutions to the growing problems of interpersonal relations in our society. Furthermore Johnson (1991) contends that: "When the child grows up, he will also have the tendency to put his shadow upon his own children. The Bible tells us that the sins of a man shall be visited unto the third and fourth generation" (p. 34). Miller (1995) claimed that it is crucial that the adult selves retrospectively condemn the abuse perpetrated by their parents. Only then can it be ensured that the victim does not one day become the perpetrator, repeating the cycle of abuse with his or her own children.

It is therefore remarkable that the participants in this study showed so much strength despite non-conducive environments in many cases. Passion's decision to be a good father even serves as an example of someone who consciously decided not to repeat the cycle of neglect.

Well-developed maternal qualities were indicated in these black mothers, and perhaps they were the saving grace of some of the participants. Miller (1995) believed that if a child is lucky enough to grow up with a mirroring, available mother who is at the child's disposal – that is, a mother who allows herself to be made use of as a function of the child's development – then a healthy self-feeling can gradually develop in the growing child.

In addition to an unfavourable environment, some patients had to cope with severe setbacks and physical and emotional hurt as children. It was a terrible loss for Busi when her father died at the Amatikulu Hospital whilst both were hospitalised there. Mali was traumatised after her hands became clawed and she was separated from her sisters. Although Ziqie developed claw hands at the age of seven, a general practitioner could still not diagnose her by the age of twelve. She was deeply saddened as a child when people looked at her strangely, and when nursing personnel were too afraid to come near her or touch her. Jalo experienced immense physical suffering at the age of fifteen. He also looked peculiar, and he isolated himself when some acquaintances laughed at him.

As discussed in chapter three, Antonovsky (1996b) suggests that exposure to traumatic life events occurring in childhood is a strong predictor of SOC. Stressors that occur before adulthood are the most influential in the development of SOC. Participants who encountered severe stressors during childhood, were most likely to have a weak SOC as adults. Although participants who experienced childhood stressors were more likely to have a frail SOC, the residual effect of these life events in adulthood can be buffered by having someone to confide in and to make them feel loved. This correlates with the impact of positive mother figures as suggested earlier on.

Other hardships that participants had to deal with created hardiness. For example, losses that some of the participants experienced were: Grace went through a divorce; Sara's husband and two brothers passed away; Mali's child and partner died; Janie and Peter had to deal with the emotional pain of their partner; none of the participants ever had the opportunity of being assisted by a psychologist in dealing with the diagnosis of leprosy.

According to Bandura (1982), individuals do not behave optimally, even though they know full well what to do. Thus, self-efficacy is concerned with how individuals judge their capabilities and how, through their self-perception of efficacy, they influence their

behaviour and motivation. A high level of self-efficacy and associated internal locus of control was clearly present in the participants and contributed to positive perceptions and actions. George had a positive outlook on life and although he experienced despair at times, he had perseverance. Grace was positive about herself. Passion believed that this disease did not really influence his self-image in a negative way. His self knowledge and an accompanying belief in his ability to cope with leprosy were the tools he used to make sense of the disease. Sara felt that she knew herself well and that she loved herself. A common characteristic shared by the participants was self-assertiveness. Mali, for example, had been harassed by two men and she laid a charge at the police and consulted an attorney with regard to this matter. The fact that Peter had always been straightforward encouraged others to ask him for advice. Inner strength was another apparent characteristic. Busi focused on her strengths. Zigie believed that she was strong and that nobody could move her. She also wanted to tell disabled people that one has to have a fighting spirit.

However, it is important to note that although the participants came across as efficient copers, this does not imply that they are super-human. For example, the researcher observed symptoms of anxiety in Sara during the interview. Sister E also told the researcher that, Zigie, at times, felt angry with God about the disease. During the interview, she started crying. It was obvious that she was still touched by her past losses. Peter was struggling with life's issues, and Passion and Grace admitted that they sometimes found it difficult to trust people.

ENTRAPMENT VERSUS TRANSCENDENCE

It seemed as if the participants cherished the ideal of becoming rescuers of others, instead of being victims of the illness. Although they were the ones who might have needed comfort, they opted to give support and comfort to others. For example, Grace was able to transcend her difficulties, and believed that she had a role to play in shaping her destiny and that of others. She qualified as a nurse and saw it as her life's task to

console downhearted people. Busi wanted to progress to standard ten to become a nurse. As a learner, Jalo had a dream of becoming a doctor and is currently studying to be a lawyer.

Busi reciprocated her friends' kindness by transcending her difficulties and supporting her friends by, for example, looking after their children. She also mentioned that people could not believe that she had such a beautiful big home. She was therefore able to transcend the stigmatisation of the community. Sara was able to transcend her difficulties and wanted to do something to help people, for example, she took care of a patient's infected foot. Ziqie felt that the incident with the headmaster had helped her to transcend her circumstances, and to convey a positive message that one had to put the past behind. She had the desire to teach people to work effectively with their hands. Initially it was difficult for Janie to adjust, but she did transcend the problem of leprosy by entering into a process of acceptance, since she realised that Peter had been sick and that nothing could be done about the decline in sexual performance on his side. The relief of being sure about the nature of the disease motivated George to advise people whom he suspected of having leprosy to go to the clinic. Passion believed that instead of dwelling on the negative side of the disease, transcendence was essential in order to fulfil a societal responsibility. He stated that by focusing one's mind on the disease, one would become unhappy and nasty to other people.

Viviers (2005) maintains that new meanings can be derived from the experience of illness which may result in a new and positive attitude towards life. Generally speaking, the participants in this study were able to derive meaning from the disease and religious beliefs seemed to play a dominant role in this regard. The new purpose and meaning the participants found through the illness, also seemed to indicate that they came to terms with their losses and reached some form of acceptance. This relates to Antonovsky's (1987c; 1996b) suggestion that a strong component of meaning indicates that life makes sense emotionally, that at least some of the problems are synergistic, but of unequal salience.

Besides Passion, all the participants transcended their agony by dealing with leprosy on a religious level. The participants' stories highlighted a strong connection with their Creator, whom they regarded as a spiritual anchor. Their experience of making meaning of leprosy was deeply rooted in their reconnection with their Creator and their religious beliefs. Grace had to escape from her channel of limitations to a broader connectedness to someone bigger than herself. Eventually, she found peace and purpose in her faith that God wanted to use her as an example to show his greatness by inflicting this disease on her.

Mali also believed that God had given her leprosy, and therefore she had to accept what came from God. The purpose of her suffering was for God to show her that she should love Him more, and be thankful. The disease gave Mali the opportunity to experience spiritual enrichment. She stated that her goal was to do what God wanted her to do, because only then would things work out as they should. She was not angry with God. Grace, Mali and Peter explained that they depended primarily on God. As Grace declared: "Dependency on God comes first; then he gives me the power to be independent." Grace and Peter always had hope, and eventually, they found peace in their faith. Peter believed that God allowed this spiritual trial "to slow him down". Busi believed that, because of her prayers, God had helped her to manage the disease. Sara suggested that physical pain disappeared once she prayed. Peter shared her active approach by praying a lot and reading the Bible. Busi stated that for her the meaning of the disease was that it strengthened her belief in God. Sara was happy, and believed that God did not create her to have leprosy; He created her rather to have faith in Him. Like Mali, she believed that God created her to fight the disease and to overcome her suffering. Peter and Janie believed that God allowed illness to make them strong. Ziqie asked God to help her to forget about the past, and He did. Peter was able to transcend his problems and had an accompanying ability to be generative as he is the spiritual father of many ministers. He also indicated that he addresses his physical problem predominantly on a spiritual level. Peter derived great meaning in life from the spiritual work he does. He stated that as a Christian, you put your hope in God and you do not

give up. Janie alleged that she had developed as a Christian during the course of her disease and that her belief in God had helped her a great deal. Her ultimate goal in life was to live for the Lord, her family and the church members. George was able to embrace the fact that God knew that he would contract this disease and how long it would last. God decided that he had to live with leprosy; therefore he had nothing to object about in future. In order to cope, he invested in God. He believed that the answer lay in surrendering to God, and abiding by God's plans for him. He grew in confidence. Jalo attributed his ability to cope partly to a divine intervention as God had given him lots of true friends who supported and respected him. Passion was the only participant who described himself as a non-practising Christian and he therefore did not see spirituality as a means of managing the disease.

The participants' faith and strong connection with God in a sense became a double-edged sword. On the one hand, religion served as a pillar of strength and created hope, but on the other hand passages in the Bible led to stigmatisation. The participants had an amazing ability to avoid harbouring resentment towards the interpretation of these passages. They also showed tolerance where faith did not have immediate results. For example, Ziqie's body was washed in front of other church members in Clermont but despite this "failure", she still believed. It was, however, not the prerogative of the researcher to confront their belief system, but rather to respect the participants' belief systems and the way in which it helped them cope.

Gibran (1956, p. 26) wrote:

The deeper that sorrow carves into your being, the more joy you can contain. Is not the cup that holds your wine the very cup that was burned in the potter's oven? When you are sorrowful, look again in your heart, and you shall see that in truth you are weeping for that which has been your delight.

The agony of participants was intense and on various psychosocial levels. Although not implied, valuable meanings surfaced.

Grace discovered her inner strength. She established that she was a person with endurance and coping skills. She learned perseverance. She learned to humble herself. Busi and Sara believed that leprosy had made them stronger. Sara made a decision that whatever disease came her way, she would fight it, particularly because she was able to win over a strange disease like leprosy. Sara needed people to help her with practical tasks. Sometimes she could not wash with one hand, but if there was no one, she tried anyway. Leprosy forced Peter to humble himself, to ask people to help him with practical things. Mali claimed that the disease helped her to be "clever". A sense of self-acceptance came to her. Although her body was hurt, Ziqie was able to think about her future in a positive way. Janie felt empowered as she stated that she had become aware of previously unknown strengths. George and Jalo grew in self-acceptance and self-confidence. Jalo felt peace as he grew from a state of hopelessness to a state of feeling in control.

DEPENDENCE VERSUS INDEPENDENCE

In dealing with a chronic disease, there is always the danger lurking that the sufferer might become dependent on something or someone. Stafford and Hodgkinson (1998, p.130) provide the following definition of dependency:

The underlying cause of dependency is alienation from the self, coupled with feelings of low self-worth and low self-esteem. The emptiness inside, which leads to pretence and denial of genuine emotions, can in time cause mental distress.

In contrast to these descriptions, all the participants shared the outstanding characteristic of being independent. The following examples from participants' stories illustrate this:

Grace construed her diagnosis as an opportunity to grow to independence. She knew that she had to depend wholly on herself and not on others: for example, she had to dress and wash herself. Mali declared that she had built her own house. Peter was frustrated that he was no longer independent and could no longer do the repairs to his home. Janie had to become much less dependent on Peter when he started to suffer from leprosy. Although George did not have children of his own, he supported his brother, sister and girlfriend financially. He dissociated a bit from the community after he contracted leprosy and depended on himself. Although Jalo was financially dependent on his mother, and he had faith in the values that his mother had instilled in him, he was not emotionally dependent on her.

Most of the participants were also financially independent. For example, a time came when Grace decided that she no longer wanted to claim workman's compensation. She decided to trust in the Lord's provision. Ziqie did not receive financial assistance from anybody. She even no longer applied for a disability pension as she had experienced difficulties with the payment of the fund and had decided to leave it.

Like Grace, other female participants showed resistance to the idea of dependency on men. When Sara's husband passed away, she realised that she had to be independent. She had learnt that from her grandmother. She believed that women should have the opportunity to make decisions independently. Sara expressed doubts about men. According to her, women have better decision making abilities. She also believed that women were more loyal. Many homes are without men, as these men have deserted their families. She stated that it was difficult for a family to function without a mother. Mali formed no trusting relationship with her partner before he died, and therefore never married him. She claimed that she did not need a man's support. She stated that she depended on herself and God only, and that she would never depend on a man. Ziqie believed that "Sometimes men are too wise". In her opinion women are much more in touch with what is happening in their homes. Even Janie, who had a good marriage, laughed during our interview and stated tongue in the cheek that women were stronger

than men when it came to handling disease. This correlates with the viewpoint of Jaffe (1990):

There is a revolution in women's consciousness. Women are seeing the world with their own eyes, neither seeking harmony with men's world view nor reacting as much in anger to it (p. 153).

PECULIARITY VERSUS SAMENESS

Self-enhancement was one of the strategies that participants employed to cope with their illness. Taylor (1983) defines self-enhancement as: the process of comparing oneself to someone else, whom one considers worse off. 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. In this study participants did not only compare themselves to others, but also compared the nature of their illness with other illnesses. The participants employed this strategy of self-enhancement in their own unique way, which served to increase their self-esteem. They concentrated on social comparison which was predominantly linked to physical appearance. This focus on physical difference might be due to the fact that persons with visible physical deformities are often ostracised socially and even reduced to the state of beggars (Anandarai, 1995). In chapter three, it was suggested that different parts of the body, especially the face, are thus more vulnerable to stigma than others (Staples, 2003).

Initially, Grace compared herself with other people and she had to fight against the feelings of negativity and physical unattractiveness. However, she came to understand that even if one is disabled, one can lead a normal life, and that there are other people who look similar. Busi stated that some people think you are useless if you get leprosy. She refused to play a patient or victim role as she told herself that she was not useless, but the same as other people. She added that she could do anything anyone else could do. She mentioned that the moment one saw oneself as a sick person, one did not

cope. Sara felt sad when the colour of her skin turned black. She stated that she looked like her grandmother. She was, however, positive at the time of the interview and she believed that her physical appearance did not have any influence on the way in which she perceived herself. Mali stated that she accepted the way she was and that she felt the same as other people. She described herself as not being a loser. Ziqie's heart used to be sore when people looked at her. She said: "I looked like an animal." She claimed that for women, the face is the most important part of the body. However, at the time of the interview, she claimed that she was at peace with the way she looked. She suggested that she knew that she was not very attractive (for example, her elder sister looked younger than her), but that she loved herself and that her face was alright. She also received social support from friends, especially Gloria and Sabi whom she had met at Amatikulu Hospital. It was easier for her to identify with them, as they were also leprosy sufferers. When George had rough skin and pimples, it was painful. It seemed as if he felt he had to compensate for his physical appearance. He admitted that he sometimes felt less confident, especially in the company of women, because of the spots on his face. By comparing himself socially, George felt that he had to compensate for his physical appearance by competing mentally with other people. In his case, social comparison had positive consequences, as it sparked off an element of self-enhancement within him. Leprosy discouraged him physically, but encouraged him to compete mentally with other people. Passion claimed that one could lead a normal life despite the diagnosis of leprosy. There was a time when Jalo did not even want to look at himself in the mirror. Although he was supported by friends, some acquaintances laughed at his facial deformities and that made him terribly sad. Jalo suggested that he knew a time would come that he would be "the same like other people". He believed that the only way in which he differed was physically.

Throughout the interviews the expression "Beauty lies in the eye of the beholder" came to the mind of the researcher. It is unthinkable that people with such a love for life cannot be called beautiful. This awareness of beauty finds resonance in the words of

Estes (1995) who takes an interesting stance towards beauty and the way in which it is interpreted:

To take much pleasure in a world filled with many kinds of beauty is a joy in life to which all women are entitled. To support only one kind of beauty is to be somehow unobservant of nature. There cannot be only one kind of songbird, only one kind of pine tree, only one kind of wolf. There cannot be one kind of breast, one kind of waist, one kind of skin (p. 202).

CONCLUSION

In this chapter the methods of coping with leprosy were discussed. Ten themes were identified in order to explain the shared and unique ways in which participants dealt with the disease.

Nietzsche's words in Frankl (1984) - "That which does not kill me, makes me stronger" (p. 103) – come to mind. Although great truth lies in these words, it is still true that it takes special people with special coping abilities to fight and conquer a could-be killer disease such as leprosy!

CHAPTER EIGHT

THE VOICES OF LEPROSY SUFFERERS HAVE SPOKEN: CONCLUSION

INTRODUCTION

In this chapter a summary of the themes identified in participants' stories will be provided. Furthermore, the study will be assessed in terms of its strengths and limitations. The researcher will conclude with supplying suggestions for caretakers of leprosy sufferers, as well as proposals for future research.

EVALUATION OF THE STUDY

The study aimed to explore the way in which SOC (Sense of Coherence) constructs manifest themselves in leprosy patients. The study gave the ten participants the opportunity to tell their stories within the context of coping with leprosy. In the individual analysis of each story the three SOC components, namely comprehensibility, manageability and meaningfulness, were used as conceptual frameworks. It is believed that the task of retelling the stories of the participants was adequately executed as the stories provided a rich account of participants' experiences of leprosy. In view of the dearth of literature pertaining to coping with leprosy the researcher believes that the information that emerged in this study could make a meaningful contribution in this regard.

The following themes were identified from the stories of the participants:

- *Confusion versus Hope*

Although most leprosy sufferers experience confusion when first diagnosed, they can gain hope through developing better comprehension or understanding of their situation and by learning to control and manage the illness more successfully.

- *Ignorance versus Knowledge*

Ignorance seems to be a debilitating factor, whilst knowledge, specifically knowledge about medical treatment and its positive consequences, plays an important role in the coping of leprosy patients.

- *Blaming versus Taking responsibility*

Acceptance and taking responsibility for their own lives, health and growth, rather than blaming others and external agents are important facets of coping behaviour among leprosy sufferers.

- *Distance versus Closeness*

Having close, supportive relationships with spouses, family and/or friends in a society where stigmatisation of leprosy sufferers is still prevalent, is an important contributing factor to the ability to cope

- *To conceal versus To reveal*

The specific context of the individual determines whether he or she is able to conceal or reveal the diagnosis and the decision of the leprosy patient must be respected as far as possible.

- *Passivity versus Activity*
Contrary to the general belief that leprosy sufferers tend to be passive, the participants in this study showed an astonishing zest for life and were active and entrepreneurial in their pursuits.
- *Weakness versus Strength*
Participants coped by focusing on their strengths rather than dwelling on their weaknesses and shortcomings.
- *Entrapment versus Transcendence*
Instead of staying trapped in the difficulties which the illness presents, participants managed to transcend their circumstances by creating meaningful spaces for themselves and even reaching out to others.
- *Dependence versus Independence*
Participants protected their independence fiercely and only accepted help from others in performing practical tasks where they had no other choice.
- *Peculiarity versus Sameness*
Although participants accepted their physical differences, they did not allow their peculiarity to diminish them as people. They still experienced positive self-esteem and saw themselves as similar to other people in that life still afforded them opportunities.

STRENGTHS OF THE STUDY

- The world of leprosy sufferers is not a context into which many psychological researchers have ventured and the study therefore makes a contribution in a relatively unexplored field.

- The findings of this study could also be of value in similar contexts of chronic illness such as HIV-AIDS.
- The participants were allowed to tell their stories in their own way as they were viewed as the experts on their experiences. In this way, the authentic voices of the leprosy sufferers themselves added an important new dimension to the information already provided by the expert voices of medical and other professionals.
- Ten participants were included in the study, which is a relatively large number for a qualitative study of this nature. It was therefore possible to hear a kaleidoscope of stories which resonated and yet provided a diversity of textured nuances.
- By exploring the way in which leprosy patients handle their disease, rich descriptions emerged of how they cope. In this study, participants' experiences were explored from a SOC perspective which allowed for the possibility of manifold realities and individual experiences.
- The researcher did not allow his own views to direct the participants as it was their stories that had to be heard. The researcher kept an open mind to allow the articulation of common themes in the study.
- The qualitative approach allowed the researcher to explain the aims of the study to the participants and this made for openness and transparency which, it is believed, profited the process.

Reliability and validity, as conceptualised in terms of a qualitative research context, were achieved in this study.

Reliability in qualitative research refers essentially to the consistency of the measuring instrument (Patton, 1990). Because field research measurements are often very personal, a situation in which the researcher allows his own concerns to cloud the research process may occur (Marshall & Rossman, 1999). It was therefore imperative that the researcher clarified his own viewpoints initially. In the study the researcher's orientation was disclosed, the social context of the study was explained, the researcher's internal processes were mentioned, the researcher engaged with the material, and themes emerged from the interviews. The data that emerged from the personal accounts of the ten participants can thus be regarded as truthful, credible and dependable.

Validity in research implies the gaining of insight into the nature of human affairs in all their complexity (Marshall & Rossman, 1999). In order to ensure validity, multiple data sources and data collection methods were employed. The relatively large number of participants in the in-depth interviews contributed to the validity. The trustworthiness of this study was improved by the validation given by the promoter and personnel of The Leprosy Mission in the interpretation of participants' stories. Furthermore, the study succeeded in assisting the readers of the research to enrich and extend their knowledge on the topics of SOC and of leprosy in adults.

On a personal note

The researcher completed a Master's dissertation on the psychosocial needs of leprosy patients. As an undergraduate student, he joined his father (who was the rehabilitation manager of the Leprosy Mission at the time) on trips to Namibia, amongst others, to promote awareness of leprosy. He also regularly visited the Westfort Hospital as a student. The researcher therefore has a long history of exposure to leprosy related issues. The parallels between his Master's study and this one serve as cross-verification of these two studies. The researcher feels that his insight into the subject of leprosy

deepened as the study progressed. There was a definite shift away from his initial views on coping with a chronic illness.

LIMITATIONS OF THE STUDY

The interpretations of the participants' stories, as mentioned earlier, were influenced by the researcher's values and viewpoints. Therefore, the researcher acknowledges that the findings of this study were coloured by the lenses through which he looked at that particular time. Another researcher may have highlighted different themes and/or included others. The findings of the study can thus not be regarded as an absolute certainty for all people suffering from leprosy. The findings of the study can also not be regarded as an absolute certainty for the participants as the interpretations of the stories were influenced by the values and beliefs of the researcher. The findings may be more accurately described as a co-construction of the stories of the participants, the researcher's viewpoint and values (his own story), and the literature consulted.

The study may be criticised if evaluated from a quantitative or empirical perspective as the findings cannot necessarily be generalised to a larger population. This type of research often gains validity at the expense of generalisability. However, it is the researcher's belief that the rich and in-depth descriptions presented here are useful to an understanding of the experience of leprosy.

Another possible limitation of the study is the fact that personal information elicited during the interviews was often of a very personal nature, which raised important ethical questions. Pseudonyms were therefore used and details were changed to protect the identity of participants and caregivers. The researcher, in recognising the sensitivity and openness of participants, ensured that they were informed beforehand of the purpose and nature of the interviews. During the interviews the researcher used his clinical judgement in reacting sensitively and empathically to their responses. Participants were encouraged to indicate when they experienced any discomfort during the interviews.

A further limitation of the study was the lack of accessibility of participants. The researcher had to travel to another province in order to interview participants. One of the participants travelled 200 kilometres to see the interviewer. Verification from participants was therefore impossible, and might serve as a source of criticism. Although some of the participants spoke English, not all were able to express themselves freely in the language. The researcher had to make use of a translator which might have resulted in misinterpretation at times. Also, the researcher is a white Afrikaner male and his cultural background is therefore quite removed from that of the participants.

Criticism might be raised against the Leprosy Mission (which is a Christian based organisation) being used to identify potential participants. However, the Leprosy Mission is the only body in Southern Africa that concerns itself primarily with the needs of leprosy sufferers.

AREAS FOR FOCUS IN CARETAKING OF LEPROSY SUFFERERS

The following guidelines emerged from the study for the caretaking of leprosy sufferers:

- The results of this study corroborated some of the findings of the earlier study (Scott, 2000) regarding the variety of emotions that follow directly after diagnosis of the illness. The implication therefore is that leprosy sufferers should receive immediate psychotherapeutic support once the diagnosis has been revealed. Therapeutic focus should be on the grief process people diagnosed with leprosy experience. Leprosy sufferers must be given the opportunity to vent their feelings. Counselors should also have a proper understanding of defense mechanisms that may be used to deal with leprosy as stressor. In some instances, traditional cognitive (mind over matter) therapy might help the leprosy sufferers to defuse their trauma. They should also not be coerced into immediately disclosing their diagnosis to others as they may need time to come to terms with the reality of the diagnosis.

- In view of what happened to some participants, segregation of leprosy sufferers, especially childhood sufferers, should not be encouraged.
- It is of the utmost importance that stories of encouragement – such as those articulated in this study – are spread to other sufferers for their encouragement. The stories should be a source of motivation and should not be presented in a patronising or condescending tone.
- The involvement of leprosy sufferers' significant others is crucial, and should be encouraged by caretakers.
- The role of institutions, for example the church, should be explored. It is of the utmost importance that the church provides information on the correct medical facts surrounding leprosy. As misinterpretation of the Bible may lead to stigmatisation, care should be taken regarding the way in which leprosy is portrayed by preachers in this modern age. Considering that religion serves as an emotional crutch for many leprosy sufferers, churches should be encouraged to provide continuous support to these individuals.
- It is essential that medical professionals are able to make a prompt diagnosis of leprosy. Furthermore, medical doctors, nursing personnel and even sangomas should be informed about developments in the field of leprosy to ensure that they are up to date on new directions in the treatment of leprosy.
- It is important that everything is done to ensure that leprosy sufferers have access to medication and that they comply with the prescribed usage. Generally speaking, fear faded the moment the participants started to recover from their symptoms. Medication contributed hugely to the participants' ability to cope with the disease.

- It is vital that leprosy sufferers have contact with other sufferers. The possibility of psychotherapeutic groups for leprosy sufferers should be explored as they derive great value from emotional support.
- The possibility of reconstructive surgery on leprosy patients should be explored.

RECOMMENDATIONS FOR FUTURE RESEARCH

The aforementioned suggestions for the caretaking of leprosy sufferers hold opportunities for future research.

- More research of a qualitative nature, describing the rich and individual responses to chronic illness, may contribute to an understanding of the experience of chronic illness. More specifically, similar studies in the field of HIV-AIDS should be conducted.
- The richness of the personal accounts in this study could stimulate further inquiry into some of the highlighted themes.
- It would be interesting to find out whether themes articulated by researchers from different cultural contexts differ markedly.
- As generalisation is not possible with a sample of this size, a larger sample would increase the chances of generalising the findings.
- Although the research was explorative, the findings could be used to compile a programme, based on SOC concepts, on how leprosy sufferers can be assisted in dealing with the disease.

CONCLUSION

This study has provided valuable information about SOC in leprosy sufferers. The participants' stories highlighted the enduring courage of individuals. Their stories rejoiced in human existence in spite of a life changing experience such as the diagnosis of a chronic illness.

Specific themes were articulated, which may prove to be worthwhile information for those dealing with leprosy sufferers. The qualitative research method proved to be a valuable method for gathering relevant information. Some important areas for future research were addressed.

AFTERTHOUGHT

I recently met the newly appointed Lucky at the offices of the Leprosy Mission when I went to collect some photographs. I enquired about Peter as I had not seen him lately. Lucky told me the upsetting news that Peter had developed deformities since I had last seen him. My immediate reaction was that this would change the story of Peter and Janie, and for that matter, of the rest of the participants.

But perhaps this is akin to looking at a kaleidoscope. The colours and shapes of these stories change all the time as a mysterious hand turns the kaleidoscope. But some colours and patterns do remain fixed. Perhaps the coping abilities are still in place: regardless of the content of Peter's story, his ability to cope may remain. In fact, he did promise that he would never sit still ...

I admire this quality in him. Just as I admire the ability of:

- Grace to embrace.
- Busi to apply entrepreneurial skills.
- Sara to forgive.

- Mali to be self assertive.
- Zigie to go forward.
- Janie to be sensitive.
- Passion to be passionate.
- George to be ambitious.
- Jalo to cherish hope.

REFERENCES

- AAP. (2000). *AAP 2000 red book*. (25th ed.). New York: American Academy of Paediatrics.
- Abu-Saad, H.H., Goldsteen, M., Proot, I.M., Spreeuwenberg, C., Ter Meulen, R.H.J. & Widdershoven, G.A.M. (2004). The needs of terminally ill patients at home: directing one's life, health and things related to beloved others. *Palliative medicine*, **18**(1), 53-61.
- Adachi, N. (1996). Charles Bonnet syndrome in leprosy; prevalence and clinical characteristics. *Acta psychiatrica Scandinavica*, **93**(4), 279-281.
- Airasian, P. & Gay, L. R. (2000). *Educational research: competencies for analysis and application*. (6th ed.). Upper Saddle River, NJ: Prentice Hall.
- Akgun, S. & Ciarrochi, J. (2003). Learned resourcefulness moderate the relationship between academic stress and academic performance. *Educational psychology*, **23**(3), 133-143.
- Anandaraj, H. (1995). Measurement of debilitation in patients of leprosy – a scale. *Indian journal of leprosy*, **67**(2), 153-160.
- Anderson, W. (1998). Leprosy and citizenship. *Positions*, **6**(3), 707-730.
- Annels, M. (1997). Grounded theory method, part I: within the five moments of qualitative research. *Nursing inquiry*, **4**(1), 120-129.
- Antonovsky, A. (1972). Breakdown: a needed fourth step in the conceptual armamentarium of modern medicine. *Social science medicine*, **6**(1), 537-544.

Antonovsky, A. (1979). *Health, stress and coping*. San Francisco: Jossey-Bass.

Antonovsky, A. (1985). The life cycle, mental health, and sense of coherence. *Israeli journal of psychiatry and related sciences*, **22**(1), 273-280.

Antonovsky, A. (1987a). The salutogenic perspective: toward a new view of health and illness. *Advances: the journal of mind-body health*, **4**(1), 47-55.

Antonovsky, A. (1987b). *Psychological factors at work and their relation to health*. Geneva: Health Organization.

Antonovsky, A. (1987c). *Unraveling the mystery of health: how people manage stress and stay well*. San Francisco: Jossey-Bass.

Antonovsky, A. (1991). *Personality and stress: individual differences in the stress process*. Chichester: Wiley.

Antonovsky, A. (1993a). The structure and properties of the sense of coherence scale. *Social science and medicine*, **36**(6), 725-733.

Antonovsky, A. (1993b). Complexity, conflict, chaos, coherence and civility. *Social science and medicine*, **37**(8), 969-974.

Antonovsky, A. (1996a). The salutogenic model as a theory to guide health promotion. *Health promotion international*, **11**(1), 11-18.

Antonovsky, A. (1996b). The sense of coherence: a historical and future perspective. *Israeli journal of medical sciences*, **32**(1), 170-178.

Antonovsky, A., Maoz, B., Dowty, N., & Wijisenbeek, H. (1971). Twenty-five years later: an animated study of the sequelae of the concentration camp experience. *Social psychiatry*, **6**(1), 186-193.

Antonovsky, A. & Sagy, S. (1986). The development of a sense of coherence and its impact to stress situations. *The journal of social psychology*, **126**(2), 213-225.

Antony, J. & Broota, A. (1991). Self-concept of children of leprosy patients. *Journal of the Indian academy of applied psychology*, **17**(1-2), 35-39.

Augustine, V., Joseph, G.A. & Rao, P.S.S.S. (1999). Being a female leprosy patient in South India. *Indian journal of leprosy*, **71**(3), 279-284.

Awofeso, N. (1995). Effect of socio-cultural beliefs on patients' perception of leprosy. The gender factor. *Tropical and geographical medicine*, **47**(4), 175-178.

Babbie, E. (2001). *The practice of social research*. (9th ed.). Australia: Wadsworth/Thomson Learning.

Bailey, D.M. (1997). *Research for the health professional: a practical guide*. Philadelphia: FA Davis.

Bainson, K.A. & Van den Borne, B. (1998). Dimensions and process of stigmatization in leprosy. *Leprosy review*, **69**(4), 341-350.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioural change. *Psychological review*, **84**(2), 191-215.

Bandura, A. (1981). *Selbsthilfe und selbstorganisation in gesundheitswesen*. Munchen: Oldenbourg.

Bandura, A. (1982). Self-efficacy in human agency. *American psychologist*, **37**(2), 122-147.

Bandura, A. (1986). *Social foundation of thought and action: a social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall.

Bandura, A. (1988). *Reflections on nonability determinants of competence. Competence considered: perception of competence and incompetence across the life span*. New Haven: Yale University Press.

Bandura, A., Caprara, G.V., Barbaranelli, C., Gerbino, M. & Pastorelli, C. (2003). Role of affective self-regulatory efficacy in diverse spheres of psychosocial functioning. *Child development*, **74**(3), 769-782.

Behrman, N. (2000). *Nelson textbook of paediatrics*. (16th ed.). Philadelphia: WB Saunders Company.

Belsito, D.V. (2000). Current reviews of allergy and clinical. *Journal of allergy and clinical immunology*, **105**(3), 28-30.

Bennett, A. (2002). Researching youth culture and popular music: a methodological critique. *British journal of sociology*, **53**(3), 451-467.

Bennishek, L.A. & Lopez, F.G. (1997). Critical evaluation of hardiness theory: gender differences, perception of life events, and neuroticism. *Work and stress*, **11**(1), 75-87.

Benoiel, J.Q. (1996). Grounded theory and nursing knowledge. *Qualitative health research*, **6**(3), 574-590.

Benton, D.C. (1993). *Grounded theory. The research process in nursing*. (3rd ed.). Edinburgh: Blackwell Science.

Bergin, A.E. (1983). Religiosity and mental health: A critical re-evaluation and meta-analysis. *Professional psychological research and practice*, **14**(1), 232-240.

Bertine, E. (1992). *Close relationships. Family, friendship, marriage*. Toronto, Canada: Inner City Books.

Bharath, S., Raghuram, R., Shamasundar, C., & Subbakrishna, D.K. (2001). Psychiatric morbidity in leprosy and psoriasis – a comparative study. *Indian journal of leprosy*, **69**(4), 341-346.

Bian, J., Chen, W., Chen, X.S., Jiang, C., Li, W.Z., Wang, H. & Ye, G.Y. (1997). An investigation of attitudes, beliefs and behaviour of leprosy patients, family members and PHC workers towards multidrug therapy in Yangzhou and Dongtai Districts of China. *Leprosy review*, **68**(2), 155-161.

Biley, F. & Smith, K. (1997). Understanding grounded theory: principles and evaluation. *Nurse researcher*, **4**(3), 458-466.

Bloombaum, M. & Gugelyk, T. (1979). Attitudes towards leprosy. *Social process in Hawaii*, **27**(1), 68-75.

Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & quantity*, **36**(4), 391-409.

Bower, B. (2001). Plight of the untouchables. *Science news*, **160**(17), 270-272.

Bowlby, J. (1969). *Attachment and loss*. New York: Basic Books.

Boyce, W. (1985). Permanence and change: psychosocial factors in the outcome of adolescent pregnancy. *Social science and medicine*, **21**(1), 262-266.

Boyle, J.S. (1994). *Critical issues in qualitative research methods*. Thousand Oaks: Sage.

Bradley, G. & Klag, S. (2004). The role of hardiness in stress and illness: an exploration of the effect of negative affectivity and gender. *British journal of health psychology*, **9**(1), 87-95.

Brand, P. (1995). Coping with a chronic disease: the role of the mind and spirit. *Patient education and counseling*, **26**(1-3), 107-112.

Brennan, P.J. (1999). The US-Japan joint leprosy research programme meeting, San Francisco. *Leprosy review*, **70**(3), 10-12.

Broda, M. (1994). The system called 'man' is not self-enclosed. *Advances: the journal of mind-body health*, **10**(3), 12-14.

Bruce, S., Ellner, K., Rubin, H., Schroeder, T.L., Williams, Y. & Wolf, J.E. (Jr.). (2000). Armadillo exposure and Hansen's disease: an epidemiologic survey in southern Texas. *Journal of the American academy of dermatology*, **43**(2 part 1), 223-228.

Calnan, M. & Moss, S. (1984). The health belief model and compliance with education given at a class in breast self-examination. *Journal of health and social behaviour*, **25**(2), 766-780.

Caprara, A. (1998). Cultural interpretations of contagion. *Tropical medicine & international health*, **3**(12), 996-1000.

Carpenter, D.R. (1995). *Qualitative research in nursing: advancing the humanistic imperative*. Philadelphia: Lippencott.

Carpenter, D.R. (1999). *Qualitative research in nursing*. (2nd ed.). Philadelphia: Lippencott.

Charmaz, K. (1990). 'Discovering' chronic illness: using grounded theory. *Social science and medicine*, **30**(11), 122-134.

Charmaz, K. (1995). *Grounded theory. Rethinking research methods in psychology*. London: Sage.

Charmaz, K. (2000). *Handbook of qualitative research*. (2nd ed.). Thousand Oaks: Sage.

Chatterjee, R.N., Nandi, D.N., Banerjee, G., Sen, B., Mukherjee, J. & Banerjee, G. (1989). The social and psychological correlates of leprosy. *Indian journal of psychiatry*, **31**(4), 315-318.

Chauhan, N.S. & Dhar, U. (1980). A psychodynamic study of children suffering from leprosy – a preliminary communication. *Indian journal of clinical psychology*, **7**(1), 75-76.

Cilliers, F. & Coetzee, S.C. (2003). The theoretical-empirical fit between three psychological wellness constructs: sense of coherence, learned resourcefulness and self-actualisation. *South African journal of labour relations*, **27**(1), 4-24.

Cilliers, F. & Kossuth, S. (2002). The relationship between organisational climate and salutogenic functioning. *Journal of industrial psychology*, **28**(1), 8-13.

Coady, M.F. (2004). Shunned. *Commonweal*, **131**(2), 31-32.

Coe, R., Romeis, J., Tang, B. & Wolinsky, F. (1990). Correlates of a measure of coping in older veterans: a preliminary report. *Journal of community health*, **15**(1), 767-774.

Corneau, G. (1991). *Absent fathers, lost sons. The search for masculine identity*. London: Shambhala.

Cotran, A. (1999). *Robbins pathologic basis of disease*. (6th ed.). Philadelphia: WB Saunders Company.

Covey, H.C. (2001). People with leprosy (Hansen's disease) during the Middle Ages. *The social science journal*, **38**(2), 315-321.

Cowley, S. & Heath, H. (2004). Developing a grounded theory approach: a comparison of Glaser and Strauss. *International journal of nursing studies*, **41**(2), 141-151.

Cutcliffe, J.R. (2000). Methodological issues in grounded theory. *Journal of advanced nursing*, **31**(1), 1476-1484.

Damico, J.S. & Simmons-Mackie, N.N. (2003). Contributions of qualitative research to the knowledge base of normal communication. *American journal of speech-language pathology*, **12**(2), 144-154.

Deal-Williams, V. (2003). What is ethnography? *ASHA leader*, **8**(5), 14-17.

Degner, L.F. & Woodgate, R.L. (2003). Expectations and beliefs about children's cancer symptoms: perspectives of children with cancer and their families. *Oncology nursing forum*, **30**(3), 479-491.

Denzin, N.K. (1989). *The research act: a theoretical introduction to sociological methods*. Englewood cliffs, NJ: Prentice Hall.

Desikan, K.V. (1997). The risk of relapse after multidrug therapy in leprosy. *Leprosy review*, **68**(2), 38-46.

De Villiers, T. (2006). Personal communication, 3 June 2006.

Dossey, L. (1994). Antonovsky's perspective may not go far enough. *Advances: the journal of mind-body health*, **11**(2), 13-16.

Dreher, H. (1995). The social perspective in mind-body studies: missing in action? *Advances: the journal of mind-body health*, **11**(2), 39-45.

Dunnagan, T., Peterson, M. & Wilson, J. (1997). Qualitative evaluation techniques and wellness programming. *American journal of health studies*, **13**(4), 205-215.

Estes, C.P. (1995). *Women who run with the wolves. Contacting the power of the wild woman*. London: Rider.

Fawcett, J. (1995). *Analysis and evaluation of conceptual models of nursing*. Philadelphia: FA Davis.

Feldman, S. (1998). *Sleisenger & Fordtran's gastrointestinal and liver disease*. (6th ed.). Philadelphia: WB Saunders Company.

Filice, G.A., Greenberg, R.N. & Fraser, D.W. (1977). Lack of observed association between armadillo contact and leprosy in humans. *American journal of tropical medical hygiene*, **26**, 137-139.

Fine, P.E.M. & Warndorpf, D.K. (1997). Leprosy by the year 2000. What is being eliminated? *Leprosy review*, **68**(3), 3-4.

Fossey, E., Harvey, C., McDermott, F. & Davidson, L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand journal of psychiatry*, **36**(6), 717-732.

Frankenhoff, C. (1998). Antonovsky's sense of coherence concept: an instrument for primary prevention in social work services. *International social work*, **41**(4), 511-523.

Frankl, V.E. (1984). *Man's search for meaning*. New York: Washington Square Press.

Frist, T.F. (2000). Stigma and societal response to leprosy: experience of the last half century. *Indian journal of leprosy*, **72**(1), 1-3.

Frohlich, K. & Potvin, L. (1999). Health promotion through the lens of population health: toward a salutogenic setting. *Critical public health*, **9**(3), 211-223.

Fullard, J.J.P. (1992). *Psychosocial pathways to health*. Port Elizabeth: University of Port Elizabeth.

Gibbs, M.S. (1989). Factors in the victim that mediate between disaster and psychotherapy: a review. *Journal of traumatic stress*, **2**(4), 154-165.

Gibran, K. (1956). *The prophet*. Melbourne: William Heinemann Ltd.

Gilner, J.A. (1994). Reviewing qualitative research: proposed criteria for fairness and rigor. *Occupational therapy journal of research*, **14**(1), 178-190.

Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley: Sociology Press.

Glaser, B. (1992). *Emergence vs forcing: basics of grounded theory analysis*. Mill Valley: Sociology Press.

Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Goldman, C. (2000). *Cecil textbook of medicine*. (21st ed.). New York: WB Saunders Company.

Gordon, J.S. (1994). The social roots of the wellness movement. *Advances: the journal of mind-body health*, **10**(3), 15-20.

Goto, M., Hagio, S., Kimura, T., Kitajima, S., Sato, E., Tokunaga, H., Ueda, K. (1995). Neuropathological analysis of dementia in a Japanese leprosarium. *Dementia*, **6**(3), 157-161.

Gruman, J. (1994). Antonovsky gives us no purchase on action. *Advances: the journal of mind-body health*, **10**(3), 19-22.

Gussow, Z. & Tracy, G.S. (1968). Status ideology and adaptability to stigmatized illness: a study of leprosy. *Human organisations*, **27**(1), 316-325.

Harman, W.W. (1994). A different sort of inner work: a response to Antonovsky's challenge. *Advances: the journal of mind-body health*, **10**(3), 439-450.

Harrison, M. (1997). *Hardiness, work support, and psychological distress in French-speaking nursing assistants in Quebec*. Unpublished master's dissertation, University of Montreal, Montreal.

Henwood, N. & Pidgeon, N.F. (1996). *Handbook of qualitative research methods for Psychology and the Social Sciences*. Leicester: The British Psychological Society.

Hollis, J. (1993). *The middle passage. From misery to meaning in midlife*. Toronto, Canada: Inner City Books.

Holloway, I. & Wheeler, S. (1996). *Qualitative research for nurses*. Oxford: Blackwell Science.

Holm, J.E. & McSherry, W.C. (1994). Sense of coherence: its effects on psychological and physiological processes prior to, during, and after a stressful situation. *Journal of clinical psychology*, **50**(1), 355-360.

Holtzman, E. (2005). Living with a chronic illness. Via the Internet www.umass.edu/fsap/articles/ill.html, 1-2.

Huang, C. (1995). Hardiness and stress: a critical review. *Maternal child nursing journal*, **23**(3), 467-489.

Hutchinson S.A. (1993). *Nursing research: a qualitative perspective*. (2nd ed.). New York: National League for Nursing.

Ishida, Y., Pecorini, L. & Guglielmelli, E. (1999). A case of reconstruction of saddle nose deformity in leprosy. *Nihan Hansenbyo Gakkai Zasshi*, **68**(3), 201-205.

Jacyk, W.K. (1986). *Leprosy in Africans. A pictorial documentation based on photographs selected and annotated by W.K. Jacyk, MD*. Würzburg: Deutsches Aussätzigen-Hilfswerk.

Jaffe, L.W. (1990). *Liberating the heart. Spirituality and Jungian psychology.* Toronto, Canada: Inner City Books.

Ji, B. (1998). Multidrug therapy for multibacillary leprosy can be shortened to 12 months. *Leprosy review*, **69**(2), 7-10.

Johnson, G.A. (1995). *Sense of coherence, perceived health and the performance of health-promoting behaviours.* Unpublished doctoral thesis, Boston College, Boston.

Johnson, R.A. (1991). *Owning your own shadow. Understanding the dark side of the psyche.* San Francisco: Harper.

Jones, E.E., Farina, A. & Hastorf, A.H. (1984). *Social stigma.* San Francisco: Freeman.

Juhl, P. (1998). *Paul and Juhl's essentials of radiologic imaging.* (7th ed.). Lippincott: Williams & Wilkins.

Kanter, I. (1976). Social psychiatry and the holocaust. *Journal of psychiatry and Judaism*, **1**(1), 35-48.

Kaplan, G.A. & Salonen, J.T. (1990). Socioeconomic conditions in childhood and ischaemic heart disease during middle age. *British medical journal*, **301**(1), 57-72.

Katoch, V.M. (1998). Is there a microbiological rationale for single-dose treatment of leprosy? *Leprosy review*, **69**(1), 6-8.

Kendall, J. (1999). Axial coding and grounded theory controversy. *Western journal of nursing research*, **21**(6), 8-15.

Khorram, O., Patrizio, P., Swerdloff, R. & Wang, C. (2001). Commentary: reproductive technologies for male infertility. *Journal of clinical endocrinology and metabolism*, **86**(6), 2373-2375.

Kirkevold, M. & Lomborg, K. (2003). Truth and validity in grounded theory – a reconsidered realist interpretation of the criteria: fit, work, relevance and modifiability. *Nursing philosophy*, **4**(3), 189-201.

Knight, E.L., Laudet, A.B., Magura, S., Mahmood, D., Rosenblum, A. & Vogel, H. S. (2003). Mediators of effectiveness in dual-focus self-help groups. *The American journal of drug and alcohol abuse*, **29**(2), 301-322.

Kobasa, S.C. (1979a). Personality and resistance to illness. *American journal of community psychology*, **7**(4), 413-423.

Kobasa, S.C. (1979b). Stressful life events, personality and health: an inquiry into hardiness. *Journal of personality and social psychology*, **37**(1), 1-11.

Kobasa, S.C. (1982). *Social psychology of health and illness*. Hillsdale, NJ: Erlbaum.

Kobasa, S.C. & Maddi, S.R. (1984). *The hardy executive: health under stress*. Homewood, IL: Cow Jones-Irvin.

Kobasa, S.C. & Pucetti, M.C. (1983). Personality and social resources in stress resistance. *Journal of personality and social psychology*, **45**(4), 839-850.

Kopparty, S.N.M. (1995). Problems, acceptance and social inequality: a study of the deformed leprosy patients and their families. *Leprosy review*, **66**(3), 239-249.

Kosa, J., Zola, I. & Antonovsky, A. (1969). *Poverty and health*. Cambridge: Harvard University Press.

Krause, N. & Van Tran, T. (1989). Stress and religious involvement among older black men. *Journal of gerontology*, **44**(1), 44-59.

Krishnatray, P.K. & Melkote, S.R. (1998). Public communication campaigns in the destigmatization of leprosy: a comparative analysis of diffusion and participatory approaches. A case study in Gwalior, India. *Journal of health communication*, **3**(4), 327-344.

Kroumpouzou, G. & Cohen, I.M. (2001). Dermatoses of pregnancy. *Journal of the American academy of dermatology*, **45**(1), 1-19.

Kubler-Ross, E. (1969). *On death and dying*. New York: Scribner.

Larson, D.B., Pattison, G.E., Blazer, D., Omran, A.R. & Kaplan, B.H. (1986). Systematic analysis of research on religious variables in four major psychiatric journals, 1987-1982. *American journal of psychiatry*, **143**(1), 763-770.

Leedy, P.D. (1997). *Practical research: planning and design*. (6th ed.). Columbus, Ohio: Prentice-Hall.

Le Grand, A. (1997). Women and leprosy: a review. *Leprosy review*, **68**(3), 203-211.

Lemaster, J.W. & Roche, P. (2000). Are we any closer to being able to measure leprosy exposure? *Leprosy Review*, **71**(1), 13-16.

Lemons-Estes, F., Neafie, R.C. & Meyers, W.M. (1999). Advances in military dermatology. *Dermatologic clinics*, **17**(1), 151-152; 155-156.

Lenderking, W.R. & Levine, S. (1995). In memory of Aaron Antonovsky: 1923-1994. *Advances: the journal of mind-body health*, **11**(3), 69-72.

Levenstein, S. (1994). Wellness, health, Antonovsky. *Advances: the journal of mind-body health*, **10**(3), 26-30.

Levine, N. & Paniker, U. (2001). Dapsone and sulfapyridine. *Dermatologic clinics*, **19**(1), 79-86.

Lindberg, M.A. (2002). The role of suggestions and personality characteristics in producing illness reports and desires for suing the responsible party. *The journal of psychology*, **136**(2), 125-140.

Lockwood, D.N.J. (1997). Rifampicin/minocycline and ofloxacin (ROM) for single lesions. *Leprosy review*, **68**(4), 5-6.

Lonner, W.J. & Berry, J.W. (1986). *Field methods in cross-cultural research*. London: Sage.

Lorig, K. (1989). The beneficial outcomes of the arthritis management course are not adequately explained by behavior change. *Arthritis and rheumatism*, **32** (1), 91-95.

Mail & Guardian. (1997, 9 June, p. 9). Last outpost of an ancient affliction.

Mandell, P. (2000). *Principles and practice of infectious diseases*. (5th ed.). Livingstone: Churchill Livingstone Inc.

Marlowe, S.N. & Lockwood, D.N. (2001). Update on leprosy. *Hospital medicine*, **62**(8), 471-476.

Marshall, C. & Rossman, G.B. (1999). *Designing qualitative research*. (3rd ed.). London: SAGE Publications.

Martinez, E., Collazos, J., & Mayo, J. (1999). Hypersensitivity reactions to Rifampin. *Medicine*, **78**(6), 361-370.

Mason, J. (1975). A historical view of the stress field. *Journal of human stress*, **1**(6), 235-251.

May, K.A. (1996). Diffusion, dilution, or distillation?: the case of grounded theory method. *Qualitative health research*, **6**(3), 543-566.

Mays, N. & Pope, C. (1995). Rigour in qualitative research. *British medical journal*, **3**(11), 767-772.

McCallin, A.M. (2003). Research: designing a grounded theory study: some practicalities. *Nursing in critical care*, **8**(5), 203-209.

McCann, T.V. (2003). Grounded theory in nursing research: part 1 – methodology. *Nurse researcher*, **11**(2), 7-19.

McDougall, A.C. (1997). Recent developments in the chemotherapy of leprosy. *Leprosy review*, **68**(4), 4-8.

McDougall, A.C. (1998). International leprosy congress; Beijing: working toward a world without leprosy. *Leprosy review*, **69**(4), 15-17.

McLane, L., Jones, K., Lydiatt, W., Lydiatt, D., & Richards, A. (2003). Taking away the fear: a grounded theory study of cooperative care in the treatment of head and neck cancer. *Psycho-oncology*, **12**(1), 474-490.

Meadows, K.A. (2003). An introduction to qualitative methods. *British journal of community nursing*, **8**(10), 464-469.

Middleton, A. (1998). *Allergy: principles and practice*. (5th ed.). St. Louis: Mosby-Year-Book Inc.

Miles, M.B. & Huberman, A.M. (1994). *Handbook of qualitative research*. Thousand Oaks, CA: Sage.

Miller, A. (1995). *The drama of being a child*. London: Virago Press.

Mitchell, P K., Peil, M. & Rimmer, D. (1982). *Social science research methods: an African handbook*. Great Britain: Hodder & Stoughton.

Monick, E. (1991). *Castration and male rage. The phallic wound*. Toronto, Canada: Inner City Books.

Morrison, A. (2000). A woman with leprosy is in double jeopardy. *Leprosy review*, **71**(2), 128-143.

Morse, J.M. (2002). *Using grounded theory in nursing*. New York: Springer.

Morse, P.A. & Field, J.M. (1998). *Nursing research of qualitative approaches*. Cheltenham: Stanley Thornes.

- Mouton, J. (2001). *How to succeed in Master's & Doctoral studies. A South African guide and resource book*. Pretoria: Van Schaik.
- Nadeau, S.E. (2002). Neurologic manifestations of systemic disease. *Neurologic clinics*, **20**(1), 57-76.
- Navon, L. (1996). Internal exclusion of leprosy sufferers: dual ambivalence and its theoretical implications. *Qualitative sociology*, **19**(4), 453-470.
- Navon, L. (1998). Beggars, metaphors, and stigma: a missing link in the social history of leprosy. *Social history of medicine*, **11**(1), 89-105.
- Nehra, A. & Moreland, R.B. (2001). Neurologic erectile dysfunction. *Urologic clinics of North America*, **28**(2), 8-35.
- Ness, R.C. & Wintrob, R.M. (1980). The emotional impact of fundamentalist religious participation. *American journal of orthopsychiatry*, **50**(2), 302-315.
- Newman, M.A. (1979). *Theory development in nursing*. Philadelphia: F. A. Davis Co.
- Noble, A. (2001). Disease syndromes in travelers. *Textbook of primary care medicine*. (3rd ed.). St. Louis: Mosby Inc.
- Obregon, D. (1996). The social construction of leprosy in Colombia, 1884-1939. *Science, technology and society*, **1**(1), 1-23.
- O'Brien, K. (2000). The healing touch. *America*, **182**(20), 22-24.
- O'Connor, W. & Nazroo, J. (2002). *Ethnic differences in the context and experience of psychiatric illness: a qualitative study*. London: The Stationary Office.

Ogden, J.A. & Porter, J.D.H. (1999). Leprosy: applying qualitative techniques to research and intervention. *Leprosy review*, **70**(2), 9-13.

Olivier, H.R. (1987). Psychiatric aspects of Hansen's disease (leprosy). *Journal of clinical psychiatry*, **48**(12), 477-479.

Orr, E. & Westman, M. (1990). *Learned resourcefulness in coping skills, self-control and adaptive behaviour*. New York: Springer.

Orth-Gomer, K. (1994). Individual and environmental resources for health promotion: interactive effects. *Advances: the journal of mind-body health*, **10**(3), 29-32.

Oulette, S.C. (1993). *Handbook of stress; theoretical and clinical aspects*. (2nd ed.). New York: Free Press.

Pandya, S.S. (2001). "Very savage rites" suicide and the leprosy sufferer in nineteenth century India. *Indian journal of leprosy*, **73**(1), 27-36.

Parizhskaya, M., Youssef, N.N., Di Lorenzo, C. & Goyal, R.K. (2001). Clofazimine enteropathy in a paediatric bone marrow transplant recipient. *Journal of paediatrics*, **138**(4), 574-576.

Patton, M.Q. (1990). *Qualitative evaluation and research methods*. (2nd ed.). London: SAGE Publications.

Pender, N., Sechrist, K., Stromberg, & Walker, S. (1990). Predicting health-promoting lifestyles in the workplace. *Nursing research*, **39**(6), 231-244.

Pincus, T. (1994). Data confirm the social context of disease. *Advances: the journal of mind-body health*, **10**(3), 32-36.

Porter, S. (1996). *The research process in nursing*. (3rd ed.). Edinburgh: Blackwell Science.

Punch, K.F. (1998). *Introduction to social research: quantitative and qualitative approaches*. Thousand Oaks, CA: Sage.

Raju, M. S. & Kopparty, S.N.M. (1995). Impact of knowledge of leprosy on the attitude towards leprosy patients: a community study. *Indian journal of leprosy*, **67**(3), 259-272.

Raju, M.S. & Reddy, J.V.S. (1995). Community attitude to divorce in leprosy. *Indian journal of leprosy*, **67**(4), 389-403.

Rakel, C. (2001). *Conn's current therapy*. (53rd ed.). Philadelphia: WB Saunders Company.

Rao, S., Garole, V., Karandikar, N., Khot, S. & Walawalkar, S. (1996). Gender differentials in the social impact of leprosy. *Leprosy review*, **67**(3), 190-199.

Requena, L. & Yus, E.S. (2001). Panniculitis. Part II. Mostly lobular panniculitis. *Journal of the American academy of dermatology*, **45**(3), 12-17.

Rosenbaum, J.C. (1980). A schedule for assessing self-control behaviours: preliminary findings. *Behaviour therapy*, **11**(1), 109-121.

Rosenbaum, M. & Ben-Ari, K. (1985). Learned helplessness and learned resourcefulness: effects of noncontingent success and failure on individuals differing in self-control skills. *Journal of personality and social psychology*, **48**(1), 198-215.

Rosenbaum, M. & Jaffe, Y. (1983). Learned helplessness: the role of individual differences in learned resourcefulness. *British journal of social psychology*, **22**(1), 456-461.

Rosenbaum, J.C. & Palmon, N. (1984). Helplessness and resourcefulness in coping with epilepsy. *Journal of consulting and clinical psychologists*, **52**(2), 49-60.

Rosenbaum, M. (1988). *Handbook of life, stress, cognition and health*. New York: Wiley.

Rosenbaum, M. (1989). Self-control under stress: the role of learned resourcefulness. *Advances in behaviour research and therapy*, **11**(4), 249-258.

Rotter, J. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological monographs*, **80**(1), 35-48.

Rotter, J. (1975). Some problems and misconceptions related to the construct of internal versus external control of reinforcement. *Journal of consulting clinical psychologists*, **43**(1), 135-143.

Rotter, J. (1989). Internal versus external control of reinforcements: a case history of a variable. *American psychologist*, **45**(4), 489-493.

Rotter, J. (1992). Some comments on the "cognates of personal control". *Applied and preventive psychology*, **1**(1), 127-129.

Rubin, H.J. & Riene, S.R. (1995). *Qualitative interviewing: the art of hearing data*. Thousand Oaks, CA: Sage.

Ruddy, K. (2001). *Kelly's textbook of rheumatology*. (6th ed.). Philadelphia: WB Saunders Company.

Ryan, T.J. (2000). Dermatology in the developing world. Needs and solutions. *Dermatologic clinics*, **18**(2), 201-210.

Sabin, T.D. (1993). Facing the human face of disease. *Hospital practice*, **28**(10a), 86; 88-89.

Sagy, A. & Antonovsky, A. (1990). A somewhat personal odyssey in studying the stress process. *Stress medicine*, **6**(1), 433-440.

Sane, S. (1999). Surgery of less common conditions in leprosy. *Leprosy review*, **70**(3), 12-17.

Sapolsky, R.M. (1994). Contemplating navels as a moral failing. *Advances: the journal of mind-body health*, **10**(3), 35-40.

Schafer, W. (1996). *Stress management for wellness*. Orlando: Harcourt Brace.

Schreiber, R.S. (2001). *Using grounded theory in nursing*. New York: Springer.

Schuster, G.S. (1999). Bacterial and protozoal infections. *Infectious disease clinics of North America*, **13**(4), 797-801; 810-813.

Scollard, D. M. & Skinsnes, O. K. (1999). Oropharyngeal leprosy in art, history, and medicine. *Oral surgery, oral medicine, oral pathology, oral radiology and endodontics*, **87**(4), 463-470.

Scott Peck, M. (1990). *The road less travelled. A new psychology of love, traditional values and spiritual growth*. London: Arrow.

Scott, J.R. (1992). *Die psigososiale behoeftes van leprosepasiënte*. Unpublished master's dissertation, University of the Orange Free State, Bloemfontein.

Scott, J.R. (2000). The psychosocial needs of leprosy patients. *Leprosy review*, **71**(4), 486-491.

Seidman, I.E. (1991). *Interviewing as qualitative research*. New York: Teacher's College Press.

Shields, L. & Twycross, A. (2003). The difference between quantitative and qualitative research. *Paediatric nursing*, **15**(9), 24-25.

Smith, W.C.S. (1997). We need to know what is happening to the incidence of leprosy. *Leprosy review*, **68**(3), 2-6.

Sogunro, O.A. (2002). Selecting a quantitative or qualitative research methodology: An experience. *Educational research quarterly*, **26**(1), 3-11.

Stafford, D. & Hodgkinson, L. (1991). *Codependency. How to break free and live your own life*. London: Judy Piatkus Ltd.

Staples, J. (2003). Disguise, revelation and copyright: disassembling the South Indian leper. *Journal of the royal anthropological institute*, **9**(2), 295-315.

Staples, J. (2004). Delineating disease: self-management of leprosy identities in South India. *Medical anthropology*, **23**(1), 69-88.

Steiner, M., Salvadori, M., Concepcion, K., Gimino, V., Kamat, D., Sibilia, S., & Fink, S.M. (2001). Commentary. *Paediatrics in review*, **22**(1), 7-22.

Stein, S. & Blochman, L.G. (1963). *Alone no longer: the story of a man who refused to be one of the living dead!* New York: Funk & Wagnalls.

Stern, P.N. (1994). *Critical issues in qualitative research methods*. Thousand Oaks: Sage.

Stevens, A. (1 999). *On Jung*. London: Penguin Books.

St. Louis, K.O. (1999). Person-first labeling and stuttering. *Journal of fluency disorders*, **24**(1), 1-24.

Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: grounded theory procedures and techniques*. Newbury Park, CA: Sage.

Strauss, A. & Corbin, J. (1994). *Grounded theory methodology: an overview. Handbook of qualitative research*. Thousand Oaks: Sage.

Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: grounded theory procedures and techniques*. (2nd ed.). Newbury Park, CA: Sage.

Strümpfer, D.J.W. (1990). Salutogenesis: a new paradigm. *South African journal of psychology*, **14**, 45-52.

Strümpfer, D.J.W. (1995). The origins of health and strength: from “salutogenesis” to “fortigenesis”. *South African journal of psychology*, **25**(2), 81-89.

Strümpfer, D.J.W. (2003). Resilience and burnout: a stitch that could save nine. *South African journal of psychology*, **33**(2), 69-79.

Tare, S.P. (1991). Community-based rehabilitation for the leprosy cured. *Indian journal of disability and rehabilitation*, **5**(2), 53-56.

Taylor, C. (2002). Assessing patients' needs: does the same information guide expert and novice nurses? *International nursing review*, **49**(1), 11-20.

Taylor, S.E. (1983). Adjustment to threatening events. A therapy of cognitive adaption. *American psychologist*, **11**(1), 1161-1173.

Van Beers, S.M. (1999). Patient contact is the major determinant in incident leprosy: implications for future control. *International journal of leprosy and other mycobacterial diseases*, **67**(2), 119-128.

Viviers, L.J. (2005). *The different voices of chronic illness*. Unpublished master's dissertation, University of South-Africa, Pretoria.

Walsh, C. (1998). *Campbell's urology*. (7th ed.). Philadelphia: WB Saunders Company.

Wang, C. H. (1997). Quality of life and health for persons living with leprosy. *Nursing Science Quarterly*, **10**(3), 144-145.

Watts, J. (2001). Japan's government compensates leprosy patients for isolation. *The lancet*, **357**(9268), 1599-1602.

Whitty, C. (1998). Mycobacterium W immunotherapy in leprosy. *Leprosy review*, **69**(3), 8-10.

Wilson, W. (1998). *Williams textbook of endocrinology*. (9th ed.). Philadelphia: WB Saunders Company.

Wills, H.W. (1992). A community health role for counseling psychologists. *Australian psychologist*, **27**(2), 96-98.

Wissing, M.P. & Van Eeden, E. (1997, September). *Psychological well-being. A fortogenic conceptualization and empirical clarification*. Paper presented at the Third Annual Congress of the Psychological Society of South Africa, Durban, South Africa.

Wissing, M.P. & Van Eeden, E. (2002). Empirical clarification of the nature of psychological well-being. *South African journal of psychology*, **32**(1), 32-44.

Wolff, A.C. (1999). Stress, social support, and sense of coherence. *Western journal of nursing research*, **21**(2), 144-157.

Woods, L. (2003). Grounded theory explained. *Nurse researcher*, **11**(2), 4-7.

Worboys, M. (2000). The colonial world as mission and mandate: leprosy and empire, 1900-1940. *Osiris*, **15**(1), 207-219.

Yanoff, O. (1999). *Ophthalmology*. St. Louis: Mosby International Ltd.

Zhu, Y. I. & Stiller, M. J. (2001). Dapsone and sulfones in dermatology: overview and update. *Journal of the American academy of dermatology*, **45**(3), 6-32.

ME R 4. **Do you have the feeling that you don't really care about what goes on around you?**

1222 1 2 3 4 5 6 7
very seldom or never very often

C R 5. **Has it happened in the past that you were surprised by the behaviour of people whom you thought you knew well?**

1221 1 2 3 4 5 6 7
never happened always happened

MA R 6. **Has it happened that people whom you counted on disappointed you?**

1221 1 2 3 4 5 6 7
never happened always happened

ME R 7. **Life is:**

2332 1 2 3 4 5 6 7
full of interest completely routine

ME 8. **Until now, your life has had:**

2331 1 2 3 4 5 6 7
no clear goals or purpose at all very clear goals and purpose

MA 9. **Do you have the feeling that you're being treated unfairly?**

1222 1 2 3 4 5 6 7
very often very seldom or never

ME R 16. **Doing the things you do every day is:**
 1312 1 2 3 4 5 6 7
 a source of deep pleasure and satisfaction a source of pain and boredom

C 17. **Your life in the future will probably be:**
 2333 1 2 3 4 5 6 7
 full of changes without your knowing what will happen next completely consistent and clear

MA 18. **When something unpleasant happened in the past your tendency was:**
 3211 1 2 3 4 5 6 7
 "to eat yourself up" about it to say "ok, that's that, I have to live with it," and go on

C 19. **Do you have very mixed-up feelings and ideas?**
 2122 1 2 3 4 5 6 7
 very often very seldom or never

MA R 20. **When you do something that gives you a good feeling:**
 1113 1 2 3 4 5 6 7
 it's certain that you'll go on feeling good it's certain that something will happen to spoil the feeling

C 21. **Does it happen that you have feelings inside you would rather not feel?**

3122 1 2 3 4 5 6 7
very often very seldom or never

ME 22. **You anticipate that you personal life in the future will be:**

2333 1 2 3 4 5 6 7
totally without meaning or purpose full of meaning and purpose

MA R 23. **Do you think that there will always be people whom you'll be able to count on in the future?**

1223 1 2 3 4 5 6 7
you're certain there will be you doubt there will be

C 24. **Does it happen that you have the feeling that you don't know exactly what's about to happen?**

2233 1 2 3 4 5 6 7
very often very seldom or never

MA R 25. **Many people – even those with a strong character – sometimes feel like sad sacks (losers) in certain situations.**

How often have you felt that way in the past?

3131 1 2 3 4 5 6 7
never very often

C 26. **When something happened, did you generally find that:**

1211 1 2 3 4 5 6 7
you overestimated or underestimated its importance you saw thing in the right proportion

MA R 27. **When you think of difficulties you are likely to face in important aspects of your life, do you have the feeling that:**

1313	1	2	3	4	5	6	7
	you will always succeed			you won't succeed in			
	in overcoming the difficulties			overcoming the difficulties			

ME *28. **How often do you have the feeling that there's little meaning in the things you do in your daily life?**

1212	1	2	3	4	5	6	7
	very often			very seldom or never			

MA *29. **How often do you have feelings that you're not sure you can Keep under control?**

3122	1	2	3	4	5	6	7
	very often			very seldom or never			

ANNEXURE 2

INTERVIEW SCHEDULE SENSE OF COHERENCE IN LEPROSY PATIENTS

- 1 In the course of the disease, were you able to understand what was happening to you?
- 2 Do you perceive future as being chaotic?
- 3 Will things work out as expected?
- 4 Are there any significant others (spouse, family, friends, etc.) who are assisting you in coping with the disease?
- 5 If you believe in a higher force, to what extent does spirituality help you to cope with leprosy?
- 6 Do you feel victimised?
- 7 Does life treat you unfairly?
- 8 Do you feel that you have a role to play in shaping your destiny?
- 9 Is there any sense in investing energy in these problems and demands?
- 10 Are these problems and demands worthy of commitment and engagement?
- 11 Are these challenges welcome, rather than burdens?

- 12 Although you are (most probably) not happy about the disease, are you willing to take up the challenge?
- 13 Do you know yourself well?
- 14 Do you believe in yourself?
- 15 How do you cope with the chronic nature of the stressor?
- 16 Are you committed to your spouse, family, friends and work, or alienated?
- 17 Do you value yourself and what you are doing?
- 18 Do you value your decision-making ability and value system?
- 19 Do you trust your abilities?
- 20 Do you have any control, a feeling that you can influence the course of events, or do you feel powerless in the face of outside forces?
- 21 Why did it happen to you (own responsibility)?
- 22 Can you act/function effectively on you own?
- 23 Are you negative and in any sense overwhelmed by events?
- 24 Are life changes the norm rather than the exception?
- 25 Is this disease a stimulus to growth or a threat to security?

- 26 Would you define traumatic events (e.g. losing your job) only as loss?
- 27 Is this disease a threat to your feeling of permanence?
- 28 Do you have the physical and moral strength required to resist or withstand the disease?
- 29 Did you become aware of previously unknown strengths and abilities?
- 30 Do you feel that you can successfully execute behaviour required to produce the desired outcome?
- 31 Do you have enduring confidence in your own capacities?

As the life history of the leprosy sufferer unfolds, other questions might include:

How do you cope with:

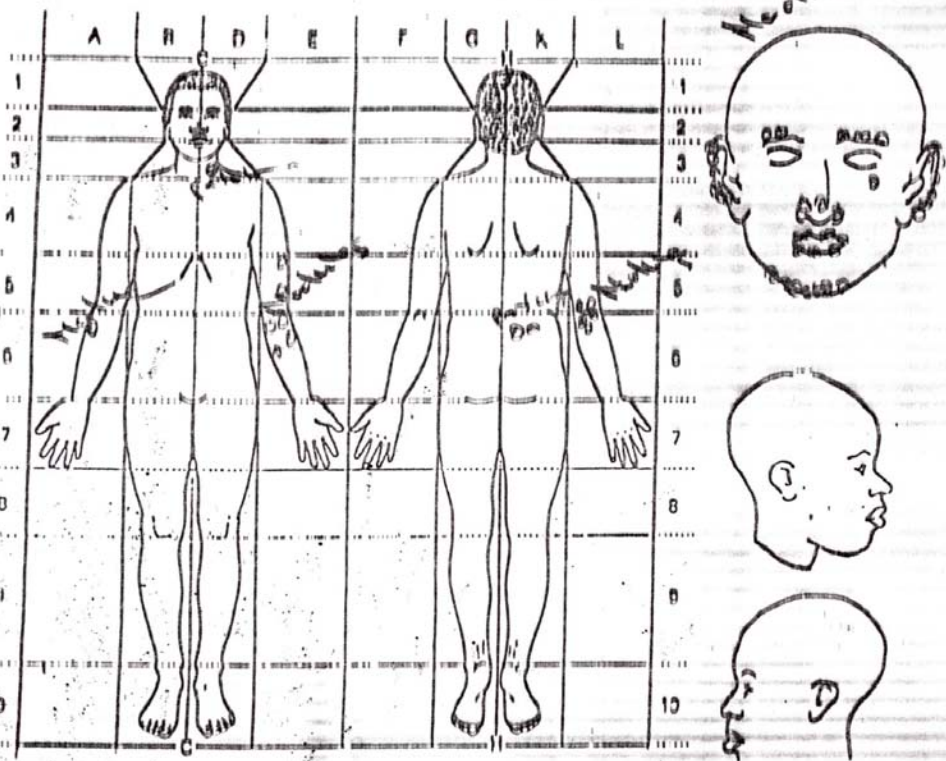
- negative feelings about the disease?
- reduction in sexual activities?
- rejection by your partner (divorce), family, friends, community?
- suicidal thoughts?
- financial problems?
- practical problems?
- ineffective treatment by medical personnel?
- loss of a job?

ANNEXURE 3

DRAWING IN JALO'S MEDICAL FILE

2. EXAMINATION OF SKIN LESIONS

Indicate sites of Lesions



3. CHARACTERISTICS OF LESIONS

Type:

Macule:	1 to 5	More than 5 ✓		
Loss of sensation:	None	Slight	Moderately	Marked
Papules:	Yes	No		
Nodules:	Yes ✓	No		
Infiltration:	Yes ✓	No		
Loss of Eyebrows:	Yes ✓	No		

Arrangement of Lesions:

A-symmetrical	Partly Symmetrical ✓	Symmetrical	Bilateral ✓	Symmetrical
---------------	----------------------	-------------	-------------	-------------

TABLE 1

Table: Education levels of Participants	
Participant	Education Level
Grace	JC 1, 2 and 3
Busi	Standard Eight (Grade 10)
Sara	Standard Eight (Form 2)
Mali	Standard Four (Grade 6)
Ziqie	None
Peter	Standard Six (Grade 8)
Janie	Standard Six (Grade 8)
George	Matric and Enrolled for LLB
Passion	Standard Eight (Grade 10)
Jalo	Matric and First-Year Sound Engineering

TABLE 2

Table: Physical Condition	
Participant	Description
Grace	Claw hands; lost one finger and another digit damaged; left leg amputated; right foot dropped.
Busi	Claw hands; nose collapsed; toe; left foot amputated. Loss of sensation caused serious damage to her hands as she constantly burnt them.
Sara	Hands looked peculiar.
Mali	Claw hands, right leg: amputated. On the other foot: only one toe.
Ziqie	Scars: hands, as well as claw. Toes: claw.
Peter	Hands: Claw like, Inability to blink.
Janie	Patches on her body.
George	Patches on left arm and back. Blisters appeared on his body. Feet burned, and a pink complexion. Rough skin and pimples. Claw hands.
Passion	Ulcers all over his body. Left hand: claw-like and without sensation. Some muscles: permanently paralysed.
Jalo	Lesions all over his body; hands felt funny; lost his eyebrows.