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The lived experiences of people living with HIV infection

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**THE LIVED EXPERIENCES OF PEOPLE LIVING WITH HIV
INFECTION**

BY

Nongluck Suwisith B.N., MSc (Public Health)

A Thesis Submitted in Partial Fulfilment of Requirements

for The Award of

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School of Nursing, Edith Cowan University

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USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Abstract

This phenomenological study was undertaken to describe the meaning of living with HIV infection. Descriptive phenomenology was utilised to investigate the lived experiences of persons who had human immunodeficiency virus infection (HIV/AIDS), describe common elements, themes or patterns of lived experiences of persons with HIV/AIDS, and analyse the meaning of lived experiences of persons with HIV/AIDS.

Twelve Australians, experiencing HIV infection and participating in the community support groups in Perth, volunteered as participants. Two participated in the pilot study. The other ten participants were interviewed individually for the main study. Intensive open-end questions pertaining to the experiences of living with HIV infection were asked during interviews which were audiotaped, transcribed verbatim, and analysed using Colaizzi's (1978) method of analysis. Significant statements were gathered and clustered into themes. Validity and reliability was confirmed during data analysis.

The phenomenon of living with HIV infection emerged as experiences of social discrimination, emotional disturbances, changes, losses, suicide attempts, and dealing with the difficulties. The experiences of living with HIV were influenced by chronic illness, terminal illness, and social stigmatisation towards people with HIV.

Roy's (1984) Adaptation Model was utilised as a second level for analysis. The Model was able to be applied to explain the experiences of living with HIV to a certain degree. Human responses to a variety of situations showed similar patterns in people living with HIV infection.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Acknowledgments

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CHAPTER ONE

Introduction

This study investigated the lived experience of selected persons who were diagnosed with human immuno deficiency virus (HIV) infection or acquired immuno deficiency syndrome (AIDS). The opening chapter highlights the significant of the study. The purpose of the research is then explained. The research question, followed by the operational definitions, is finally stated.

Background

Incidence

AIDS caused by Human Immunodeficiency Virus (HIV), was epidemically and scientifically discovered in the United States in 1981 (Croft, 1992). As the epidemic of HIV infection has been spreading globally, public health experts project that in less than a decade the global count of people with HIV infection may reach as many as 110 million (Mann, Tarrantora, & Netter, 1992).

Since AIDS was first diagnosed in Australia in December 1982 (NHMRC Working Party, 1984), the number of people with HIV infection reported has been increasing. The statistics from the National Center in HIV Epidemiology and Clinical Research (1995) have shown that 19,087 Australians were infected with HIV by March 1995. Australia then has been claimed to have the most advanced HIV epidemic of any Western country because the number of AIDS cases, as a proportion of population, is higher than other countries (Carr, 1992). The majority of these people with HIV infection were amongst those people who were homosexual and bisexual. The minority were intravenous drug users and people who had HIV transmitted via heterosexual contact.

Issues related to HIV infection

HIV infection is becoming a serious social issue in this decade. AIDS is not only viewed as an infectious disease, but it seems to be a "psychological disease" (Viney & Crooks, 1992). The infection has triggered a series of crises for steadily widening circles of people because HIV itself is incurable and transmittable. Carr (1992) pointed out that the advent of AIDS had led to a crisis for every individual, every family, every group, every institution, and every country.

Individuals infected with HIV are confronting multiple psychological issues influenced by the illness and social attitudes towards them. Although AIDS knowledge has been extensively provided to the public, negative social attitudes toward people with HIV seem to continue. Recent research has still reported irrational fear of contagion of the HIV infection from many groups of people (Breault & Polifroni, 1992; Brennan, 1988; Brenner & Kauffman, 1993; Meisenhelder, 1994; Randal, Bryce, Bertler, Pope, & Lawrenchuck, 1993).

Nonetheless, risks of HIV infection in workplaces have been recognised amongst health care workers. The number of hospitalised patients diagnosed with AIDS are increasing. This affects nurses' willingness to care for them, as nurses are one group of the health care workers spending most time caring for these patients. Recent research has reported issues of changing professions because of the risk of AIDS (Wiley, Heath, Acklin, Earl, & Barnard, 1990) and rights of nurses in refusing to care for HIV infected patients (Downse, 1991; Heric & Smith, 1989).

Trends

Advanced medical technology has been extensively implemented to prevent transmission and to help cure the infection, yet the experience of living with HIV infection has received less attention. Primarily, a number of Australian health research studies were mainly focussed on social

attitudes towards HIV infection and HIV prevention (Dowsett, 1992). This was related to the National Health Policy and Commonwealth AIDS Research Grant (Dowsett, 1992). Later, when the impact of HIV infection on individuals became heightened, studies in terms of human and social sciences were carried out in a number of disciplines.

From psychosocial research both qualitative and quantitative studies were conducted in relation to health promotion and prevention to the progressive HIV epidemic. Psychological issues associated with HIV infection and AIDS in Australia were occasionally studied, including psychological distress amongst HIV infected people (Viney, Henry, Walker & Crooks, 1989), psychological factors and the progress of AIDS (Viney & Bousfield, 1990) and suicide related to AIDS (Hassan, 1990). Little health research has been reported about the experience of people living with HIV, particularly nursing research.

It becomes an inquiry as to why this phenomenon is not of interest amongst nursing researchers in this country. This issue may not be criticised that psychosocial aspects of people living with the HIV infection are largely ignored. However, it may lead to a question as to why nurses need to know about the experiences facing their clients. Nursing paradigms portray the attempts to abandon the medical model which views a human as a part rather than as a whole (Munhall & Boyd, 1993). According to the paradigms, nursing is viewed from the perspective of human sciences rather than natural sciences. An individual is viewed as a human being who interacts with the environment (Rogers, 1970). An individual's health is described as a reflection of these interactions (Roy & Andrews, 1991). As nursing takes these humanistic and holistic ways of viewing phenomena for granted, the medical knowledge of the HIV infection itself may not be a sufficient response to the paradigms.

In addition, nursing must respond quickly, constructively and proactively in order to meet clients' needs, because the numbers of HIV infected cases are increasing rapidly. The infection seems to affect the individual's psychological and social status as well as the physical. Therefore, how the infection affects the day to day living of the people who are HIV infected needs to be captured and understood.

Significance of The Study

From this study, the knowledge of how people are affected by the HIV infection will help nurses to understand the realities of human beings and human experiences of those with HIV/AIDS. The reflection of the human experiences in living with the HIV infection will influence the meaning of an humanistically and holistically nursing perspective to society.

In addition, the aim of nursing science is to contribute to enhanced practical nursing. A quality of nursing is understanding the life events of the patient (Fjelland & Gjengedal,1994). Through the process of understanding, nursing knowledge can then be generated and may result in giving direction to nursing care.

This research was conducted in conjunction with Australian permanent residents. The knowledge gained from this study will be particularly useful for nurses in Australia. The findings will also be beneficial to other health care agencies who are actively promoting a quality of life for those with HIV/AIDS.

Purpose of The Study

The purpose of this study was to explore, describe, and interpret the experiences of persons living with HIV/AIDS in Australia. The study aimed to meet the following objectives:

1. To investigate the lived experiences of individuals living with HIV infection.

2. To describe common elements, themes or patterns of experiences of the individuals living with HIV.

3. To analyse the meaning of experiences of living with HIV infection.

Research Question

This study answered the following question:

" From the perspective of persons with HIV infection, what is the experience of living with HIV infection?"

Operational Definitions

Acquired Immuno Deficiency Syndrome, AIDS : A collection of illnesses resulting from infection with human immunodeficiency virus (Appleman & Corte, 1992).

Human immunodeficiency virus, HIV: The virus that causes AIDS by infecting human lymphocytes called T-lymphocytes (Aggleton, Homans, Mojsa, Watson & Watney, 1989).

People living with HIV infection: Any individual who was infected with HIV, regardless of the absence or presence of clinical manifestations (Nunes, Raymond, Nicholas, Leuner & Webster, 1995). For this research, any individual who identified him/herself as HIV positive was included in the study.

Lived experience: The world of everyday life which is the central focus of phenomenological inquiry (Streubert & Carpenter, 1995). It is the experience that presents to the individual as what is real in his or her life. A human lived experience consists of the commonsensical that is taken for granted and tends to be less accessible (Powers & Knapp, 1991).

Organisation of The Thesis

Chapter One provides an introduction and discussion of the significance of the study. The aims and relevant research questions are also identified, followed by the operational definitions related to this study.

Chapter Two consists of two major parts. The first part begins with a discussion why human experiences should be studied using the qualitative method. Then the literature review relevant to physical, psychological and social issues, associated with people living with HIV infection, completes Chapter Two. Chapter Three describes the methodology which includes the research design used, selection of participants for the study, method of data collection, data analysis, and ethical considerations. The findings of the study are described in Chapter Four. A discussion, related to major findings and a second level of analysis, is detailed in Chapter Five. A conclusive summary, implications for the nursing profession, limitations, and recommendations for further research, are then presented in Chapter Six.

CHAPTER 2

Literature Review

In order to place the findings of this study within the context of what is already known about the topic, the following areas have been included in the review. The literature review begins with a discussion why human experiences should be studied using the qualitative method. Selected research studies relevant to people experiencing HIV/AIDS are then reviewed to indicate where a knowledge gap has occurred.

A qualitative paradigm

A paradigm is defined as an entire repertoire of beliefs, values, laws, principles, theoretical methodologies, ways of application, and instrumentation (Meleis, 1991). Historically, two paradigms have been used to determine all phenomena in the world; natural sciences and human sciences.

In natural sciences, the preferred method is quantitative that is derived from a positivism perception that focusses on causal relationships of objects (Clarke, 1995). The quantitative paradigm aims to study objects of nature, things, natural events, and the way that objects exist (Van Manen, 1990). Empirical scientists believe that if objective measurement is unable to be assigned to a phenomenon, then the existence of the phenomenon may be in question. However, Oiler (1986) pointed out that a human being may not be seen to react in a prescribed manner after being stimulated like other subjects in scientific laboratory experiments. An individual is incomparable, unclassifiable, uncountable, and irreplaceable (Van Manen, 1990). Therefore, the quantitative paradigm may not be sufficient to explain the reality of humans in their life events.

Human sciences view the wholeness of human beings (Van Manen, 1990). The value of subjectivity, which refers to the meanings of the ways in

which people make sense of their experiences and lives, is taken into account (Munhall & Boyd, 1993). The qualitative paradigm, which is based on human sciences, aims to understand human behaviour holistically and inductively from an informant's perspective (Minichiello, Aroni, Timewell & Alexander, 1991). It offers an opportunity to study and create meaning that enriches and describes human life in context (Streubert & Carpenter, 1995). The understanding of experiences of living with HIV infection necessitates a qualitative methodology, which is committed to seeing the phenomenon from an individual experiencing HIV infection from their point of view.

Selected research studies relevant to people experiencing HIV infection

In viewing a person holistically, the selected research studies related to people experiencing HIV infection may be reviewed in terms of the physical, psychological, and social aspects of their experiences.

Physical illness. Physical problems related to HIV infection may or may not display the symptoms associated with the disease in the early stage. When the infection involves human immune systems, many symptoms become apparent and result in limited human function, such as opportunistic infections and cancer (Aggleton et al., 1989). O'Brien and Pheifer (1993) conducted a three-year longitudinal project designed to identify a data base of the physical and psychological issues related to 133 participants with an HIV infection. The authors used both structured and open-ended questions as both the quantitative and qualitative research tools. Findings showed that 55 % of the group experienced physical symptoms before diagnosis of HIV infection was made. These symptoms included such conditions as flu-like symptoms, lymphadenopathy, upper respiratory tract infection, oral infection, and pneumonia. The authors also reported that fatigue, impaired mobility, and nutritional disturbances were the most common problems that limited the participants' ability to perform

many activities, and affected what these people were expected to do or able to do.

Psychological issues. Having AIDS may not be considered the same as having other infections. Many researchers documented feelings of fear experienced by people who had an HIV infection after blood testing results were found positive (Firm, 1995; McClain & Gramling, 1992; Nichols, 1985; Salisbury, 1986). McClain and Gramling (1992) used a phenomenological approach to identify stress amongst 36 people with an HIV infection. Findings showed that the people infected with HIV who participated in their study experienced feelings of fear related to death and dying. These feelings were perceived as the major stressor. In other studies, fears of suffering in the future were also common experiences of hospitalised people who were diagnosed with AIDS (Kermode, 1995) as well as confronting mortality with the HIV infection (Remein, Rabkin, Williams & Katoff, 1992).

HIV infection also affects the interpersonal relationships of an individual. Firm (1995) conducted a qualitative study to investigate the psychological distress of patients who had a clinical diagnosis of AIDS. Findings showed that the patients experienced fear of rejection from their significant others as well as fear of disruption of relationships with others. In addition, the patients perceived the feeling of fear as significant emotional distress. Furthermore, the author reported that the emotional and psychological distress felt by these people was related to three factors; being unprepared for being told that they were HIV positive, being admitted to hospital for the first time with others who had AIDS, and the lack of information associated with their illness.

Experiences of uncertainty related to HIV infection are also reported in previous quantitative and qualitative studies. Maj (1990) used self-measurement to identify feelings of uncertainty amongst people living

with HIV infection. Results showed that the feelings of uncertainty were an actual source of anxiety, especially at the onset of the early symptoms of HIV related illnesses. The symptoms raised an awareness of an uncertain future and signalled a decline in the health and physical functioning of those with HIV infection (Chuang, Devins, Hunsley & Gill, 1989). A phenomenological approach by Coward (1994) also reported that those infected with HIV experienced living with uncertainty. Their experience was described as an inability to predict periods of their own illness or wellness and how long each would continue. A similar finding was also reported in another phenomenological study conducted by McClain and Gramling (1992) and in an ethnographic study by Laryea and Gein (1993).

People with HIV infection felt guilty following the HIV testing (Miller & Brown, 1988). The guilt feelings were related to self-devaluation with beliefs about having engaged in behaviours that resulted in the infection (Miller & Riccio, 1990). In addition, the concern about having possibly infected others prior to or after testing HIV positive was included (Catalan, 1988). Bennett (1990) reported in a phenomenological study that people with HIV infection experienced feelings of guilt when they perceived that their significant others had to care for them.

In addition, people with HIV experienced low self-esteem. According to the study by O'Brien and Pheifer (1993), the self-esteem of those with HIV infection decreased when they experienced being rejected by others, when there were changes in their self-image as a result of the physical illness, and when there was a disruption in their relationship with their significant others. A quantitative study by Turner, Hays and Coates (1993) found that the level of self-esteem was positively associated with all types of social support such as emotional, informational, and practical supports provided to people with HIV infection. Similarly, a quantitative study by Lang (1991) revealed that high levels of self-esteem of people

with HIV might have been as a result of gained support from others or from the support groups available to them.

Several researchers reported that HIV infection had implicated experiences of grief, loss, and changes to an individual (Kermode, 1995; Laryea & Gein, 1993; Martin & Dean, 1993). Martin and Dean (1993) conducted a seven year longitudinal quantitative study tracking the effects of bereavement among 746 homosexual-bisexual American men. The authors discovered that bereavement reactions to AIDS-related deaths were most pronounced amongst people who were themselves HIV infected. The experiences of loss were associated with the limited social activities and job performance (Kermode, 1995; Laryea & Gein, 1993). The precedence of illness or the death of someone with HIV infection was also a factor influencing the loss (Martin & Dean, 1993). In addition, negative attitudes toward others and toward self changes amongst people with HIV were also found (Laryea & Gein, 1993).

Tindall, Forde, Goldstein, Ross and Cooper (1994) reported changes in human sexuality related to HIV. The researchers quantitatively surveyed sexual dysfunction amongst 149 participants who had a clinical diagnosis of AIDS or AIDS related complex (ARC) in Australia. Findings showed that alteration of sexual function amongst those people with HIV was evident. Fifty three per cent indicated that they were sexually dysfunctional at the time of the survey. The developed sexual dysfunction which affected the participants' quality of life was reported since becoming HIV seropositive. The significance was found to be greater in people who were diagnosed with AIDS.

In addition, a celibate life style had been adopted by many people infected with HIV infection to avoid the risk of HIV transmission (Bennett & Koop, 1987; Seigel & Raveis (1993). However, other reasons for choosing celibacy were also found (Seigel & Raveis, 1993). These included the desire

for a more meaningful relationship than just having sex, the discovery of some difficulties in practising safe sex, the avoidance of homosexual sex habits, and the development of emotional distress. The distress largely reported was the feelings of guilt related to the fear of transmitting the infection to someone else.

Evidently, people with HIV infection are at an elevated risk for suicide. Many quantitative studies were conducted to investigate suicidal thoughts and attempts related to HIV infection. Perry, Jacobsberg, and Fishman (1990) discovered that people with HIV infection demonstrated higher levels of suicidal intentions and greater frequency of suicide attempts when compared to their non-HIV infected counterparts. The suicide attempts occurred relatively early in the disease process (McKegney & O'Dowd, 1992). Orr, O'Dowd, and McKegney (1990) found that the suicidal rates were 26-51% higher than in non HIV people and the rates in asymptomatic HIV infection were greater than in those with AIDS related conditions. Rabkin, Wilson, and Kimtin (1993) reported that the desire to die most likely occurred during the course of infection rather than attempting suicide in response to the diagnosis of HIV infection. Mazurk et al. (1988) found that most of those people infected with HIV talked of killing themselves at some time in the future, but few carried out their threats when the time came. Common factors influencing the suicidal thoughts included the experiences of physical symptoms, particularly being bed bound (Belkin, Fleishman, Stein, Piette & Mor, 1992) and depression (Kalichman & Sikkema, 1994; Mazurk et al., 1988).

Social issues. A number of negative responses to people with HIV infection has been discussed. People with HIV / AIDS experienced negative social reactions after the disclosing of their HIV status (Andrews, Williams & Neil, 1993; Bennett, 1990; Laryea & Gien, 1993) and caused those with HIV to develop a variety of psychological distresses which included

feelings of being ashamed, feelings of being lonely, depression, and loss of self-respect (Laryea & Gein, 1993). The social reactions took several forms such as being obvious, subtle, and/or covert (Bennett, 1990).

Discrimination and disruption of the relationships to others were other examples (Hays, et al., 1993; Laryea & Gein, 1993).

Eliason (1993) purported that two powerful social stigmata were related to the social reactions towards the people with HIV/AIDS. These included fear of contracting HIV and homophobia. The fear of contracting AIDS is a stigma that most believe will lead to inevitable death (Eliason, 1993). Northcott and Reutter (1991) conducted a quantitative survey of public opinions regarding AIDS policies. As a result of the public's fear of contracting AIDS, the agreed opinion was that health care workers should be screened for AIDS to protect the public, and the patients in the hospital should be screened routinely for the HIV disease. For health care providers, the fear of contagion amongst those ranged from rational concern to irrational concern (Macks, 1988). People with AIDS (PWAs) were consistency ranked low from the perspective of physicians when comparing their willingness to treat AIDS with their willingness to treat other illnesses (Yeddia, Barr & Berry, 1993). The refusal of nurses to care for patients with AIDS has also been highlighted (Plant & Foster, 1993; Van Servellen, Lewis & Leake, 1988).

Homophobia is a negative judgement about homosexual behaviour (Eliason, 1993). Several studies have identified an increase in homophobia since the AIDS epidemic began (Eliason, 1993; Douglas, Kalman & Kalman, 1985; Scherer, Wu & Haughey, 1991). HIV screening amongst homosexuals were also urged by public opinion as well as isolating them if their HIV test results were positive (Northcott & Reutter, 1991).

Coping strategies. Many authors have reported about coping strategies utilised to decrease psychological distress related to living with

HIV infection (Bennett, 1990; Hays, Turner, & Coates, 1992; McClain & Gramling, 1992; Remein et al., 1992; Seigel & Krauss, 1991). These included employing a support network from lovers and closest friends, concealing their HIV status, and comparing their experiences with others for their "self-protection" from those who rejected them (Bennett, 1990; Hays, et al., 1992; Remein et al., 1992; Seigel & Krauss, 1991). Staying healthy, controlling negative thoughts, and maintaining a positive outlook were other reported strategies (Remein et al., 1992; McClain & Gramling, 1992).

Social support can affect the quality of life of people with HIV/AIDS. The effect of HIV infection on an individual's quality of life was reported by Nunes et al. (1995). Fifty people with HIV infection participating in support groups in America were participants in their correlational design. Findings showed that the social support and quality of life were significantly interrelated to each other and that the support linked to positive health status in those people with HIV infection. In addition, the perceptions of non-supportiveness from their family and friends were associated with poor health outcomes (Stroebe & Stroebe, 1991).

Significance of conducting a phenomenological study of people experiencing HIV/AIDS in Australia

It can be seen that the physical, psychological, and social aspects of people living with HIV infection are altered. The AIDS epidemic continues to grow and to create panic, fear, anxiety, and social stigmatization against those people with HIV. Medical research related to people with HIV/AIDS has focussed on causation, mode of transmission, and treatment of the disease. Nursing research has focussed on the various aspects of nurses' knowledge, practices, and attitudes towards caring for individuals with HIV/AIDS. However, the aims of nursing are to monitor, promote health, care for patients, and assist patients to care for themselves (Melies, 1991). In the case of people living with HIV infection, nurses need to understand the

basic phenomenon of living with HIV infection so as to fulfil these goals. There are questions related to how these people experience the infection. For example, what is the meaning of life among persons infected with HIV? How does a person feel following diagnosis of the HIV infection? How does the infection affect day-to-day living?

A plethora of research about AIDS is evident. Much information is captured by using quantitative research approaches and the majority of research has been conducted in the United States of America (USA). Minimal qualitative research, particularly nursing research, has been reported in Australia where Australians' attitudes, life-styles, and social context may differ from those in the USA.

Although lived experience of Australian people with HIV infection has already been reported in a phenomenological study by Kermode (1995), the study mainly focussed on the experiences of PWAs to nursing interventions perceived when they were hospitalised. Owing to the limitations of a phenomenological study, the knowledge gained may not be generaliseable or predictable because the samples are selected and the sample size is small (Streubert & Carpenter, 1995). Therefore, the study of lived experience of people with HIV/AIDS needs to be unfolded in other aspects and various situations. The experiences of those living with HIV/AIDS outside hospital need to be explored. This study aims to investigate the lived experiences of people with HIV/AIDS and who live in the community. Consequently, the understanding of the experiences of PWAs will be considered globally, taking into account other completed studies relating to people infected with HIV.

CHAPTER THREE

Method of Investigation

In order to answer the research question of this study, a qualitative approach was undertaken. To explore the experiences of living with HIV/AIDS, phenomenology was utilised in terms of a paradigm, philosophy, and methodology.

The paradigm

Phenomenology is a paradigm that focusses on the reality of human experiences from the perspective of human sciences (Munhall, 1994).

Humanism and holism are both significant perspectives of human sciences. Humanism focusses on understanding of human beings. An holistic focus is concerned with viewing human beings as a whole. Phenomenology as a way of thinking about what life experiences are like for people, therefore, is a paradigm unfolding meanings of human experiences taken from the human sciences perspective (Van Manen, 1990). Human beings can then be understood in-depth when a description of their experiences are holistically explained (Munhall, 1994).

The philosophy

A philosophy is defined as a statement of beliefs and a speculation about the nature and value of views (Bille, 1986). It is the inquiry into the nature of things based on logical reasoning rather than on empirical methods (Marriner-Tomey, 1994). Phenomenology is also viewed as a philosophy which believes in human nature and individuals' experiences (Van Manen, 1990). The history of the phenomenological movement attempted to explain beliefs and speculation about human nature and individuals' lived experience. Merleau-Ponty (1962) postulated five key concepts of philosophical phenomenology, namely consciousness, embodiment, natural attitude, experiences, and perception.

Consciousness is a sensory awareness of and response to the environment of a person (Munhall & Boyd, 1993). Schutz cited in Boyd (1994) summarised that consciousness gives direction to a person to determine what reality is operative at any given point of time. For example, feelings, tasting, and hearing are at a conscious level that makes us aware of being-in-the world. Embodiment is explained as the relationship between mind and body, subject and object, and knowledge that comes about through one's consciousness (Munhall & Boyd, 1993). These recognitions are individually interpreted and become a part of a person's natural attitude, which is a type of mode of consciousness (Schutz, 1973). A current experience, an original mode of our consciousness, is implanted and shaped by a stock of previous experiences and interpretations in the natural attitude of each individual (Merleau-Ponty, 1962). The interpreted experience is then presented and a person then acknowledges his/her experience through his/her perception, which is the reality that the individual perceives (Munhall, 1994).

Therefore, as a philosophy, phenomenology demonstrates several key concepts concerning a human being. Meanings and interpretations depend on one's consciousness, embodiment, natural attitudes, perception, and experience of the things that have happened in one's life.

The phenomenological method

Phenomenology is a study of human 'life-world' which focuses on human experiences in each individual (Van Manen, 1990). The goal of a phenomenological method is to uncover the meaning of lived experiences through analysis, intuition, and describing a phenomenon from individual reports in the way they appear and without any preconceived notions (Parse, Coyne & Smith, 1985).

Spiegelberg (1975) identified six major elements of phenomenological investigations, which included descriptive

phenomenology, phenomenology of essences, phenomenology of appearances, constitutive phenomenology, reductive phenomenology, and hermeneutic phenomenology. Explanation of these six elements have been summarised by Streubert and Carpenter (1995) as follows:

Descriptive phenomenology is aimed to explore, analyse, and describe particular phenomena directly and freely from unexamined presuppositions. Maximum intuitive presentation is a goal set.

Phenomenology of essences are focussed on the process of exploring through the data. Common themes and essences are searched and established to form patterns of relationships shared by the particular phenomena. The insights of essential structures and relationships can then be finally obtained. *Phenomenology of appearance* involves the giving of attention to the phenomenon through dwelling with the data from different perspectives. This results in heightening a sense for the inexhaustibility of the perspectives. *Constitutive phenomenology* is the study of phenomena as they establish themselves. In this process, the phenomena takes shape in one's consciousness and the process subsequently develops the sense for the dynamic adventure in one's relationship with the world. *Reductive phenomenology* occurs concurrently throughout a phenomenological investigation when personal bias, assumptions, and presuppositions are set aside. Purest descriptions of the phenomenon is investigated. *Hermeneutic phenomenology* is designed to reveal concealed meanings found in the phenomena. The meanings are not immediately understandable, but are achieved through an individual's self-interpretation of the phenomena.

According to the six elements, Streubert and Carpenter (1995) viewed that not all steps must be adopted. Only descriptive phenomenology, phenomenology of essences, and reductive phenomenology are commonly used by many researchers. In order to study the informants' unstructured descriptions of lived experience,

individuals do not answer prepared questions as in the quantitative method. The experiences which are the raw data reflecting realities of human beings are located, observed, and described without limitations to the researchers' frame of reference (Van Manen, 1990). As a result, the uncovered concepts are more accurate, more precise, and closer to reality.

Bracketting is the activity to explicate assumptions and pre-understandings about the specific phenomenon being studied (Munhall, 1994). It is the technique used to suspend beliefs, any preconceived notions, conceptual frameworks, or expectations of an investigator in an effort to better understand the phenomenon under study. The pure essences of consciousness can then be known through the bracketting of these (Mitchell & Cody, 1993). It helps the investigator to prevent bias from intruding on the study findings.

Intuiting or grasping, is a key feature of the methodology. These refer to a mode of awareness and the processes which aim to express the situation from the viewpoint of the informant (Knaak, 1984; Rose, Beeby, & Parker, 1995). Avoidance of all criticism, evaluation, opinion, and paying strict attention to the phenomenon under investigation as it is being described are examples of the technique of intuiting (Streubert & Carpenter, 1995).

Reduction is described as concentration on the phenomenon as the researcher becomes absorbed in it through bracketting (Oiler, 1986). Field and Morse (1985) viewed that this technique led to the identification with the essence of the phenomenon. Therefore, the meaning of the experiences is led back to its source (Rose et al., 1995).

Design

This study was designed to uncover the meaning of lived experiences by exploring, describing, and interpreting a phenomenon from an individual's report. A combination of data sources which included

interviews and observation was used as research instruments. The study design was divided into two parts; a pilot study and a main study.

Pilot study. A pilot study was done to help the researcher gain more experience with the phenomenon, the methodology, and with the setting. The activities at one of the AIDS support groups were observed for at least one week to help the researcher become familiar with the staff, activities, and clients of the support group. The pilot study was also used to prepare the researcher for sample selections required for the study.

The process of learning the sublanguage was then carried out by learning from experiences of people diagnosed with HIV described to the researcher. Van Manen (1990) suggested that not only should researchers use their own personal experiences as a starting point, but researchers also needed to search for idiomatic phrases and traced etymological sources. The original meaning that might be lost as a result of using idiomatic phrases and colloquial words was learned through the verbal and written descriptions gained from the pilot study. In this case, one was in the form of verbal description and the other a written description. In addition, Streubert and Carpenter (1995) suggested that pilot interview skills could contribute to the development of interviewing skills. This part was, therefore, intended to familiarise the researcher with the language and expression of the experience and to test the method of analysis.

Main study. The main study was carried out to collect data to be used for analysis of the lived experiences of people living with HIV infection. The gathering of verbal descriptions was part of the design.

Sample

In qualitative research, only a small number of participants are required (Rissmiller, 1991). A purposive sample, the most commonly used in phenomenological inquiry (Streubert & Carpenter, 1995), was used as a method to access selected cases and obtain a rich descriptive data base.

Selecting information-rich participants for study in depth is crucial to the logic and power of purposeful sampling (Patton, 1990). Therefore, individuals who were able to share their particular knowledge of living with HIV infection were asked to volunteer their experiences. The majority of participants were obtained from the community AIDS support groups. Criteria for inclusion in the study were persons who were (a) Australian permanent residents, (b) over 18 years, (c) perceived themselves as having AIDS or HIV infection, (d) at a sufficient level of cognitive functioning to give voluntary informed consent to participate in the study, (e) able to recall and verbally convey information with reasonable clarity and accuracy, and (f) at a sufficient level of physical functioning to comfortably endure a one or two hour interview. Both male and female participants were invited to participate.

Participants were excluded if they (a) developed progressive severe illness, (b) were experiencing shortness of breath, or suffered severe fatigue and discomfort or (c) developed neurological problems.

Settings

Two AIDS community support groups in Perth, the Western Australian AIDS Council (WA AIDS Council) and the AIDS Pastoral Care, were the settings for the study. The persons with HIV/AIDS who met the criteria were interviewed in a private place either outside or inside the center to prevent distraction. This was arranged by mutual agreement between each participant and the researcher. An assurance of comfort, safety, privacy, and freedom from distractions and interruptions was the main criteria for the setting. In the study, eight interviews were held in the private room of each support centre. Three participants preferred to be interviewed at their place of residence. One interview was performed at the researcher's home.

Procedures

Once approval was granted from the Higher Degrees Committee and Ethics Committee of Edith Cowan University, the pilot study was launched. The AIDS Pastoral Care agency was the setting selected for the observation. The researcher was introduced to people with HIV infection by senior staff members of the center and was allowed to participate in many activities of the center, such as having conversations, playing games, and having lunch with those people with HIV. By these means, the participants who met the criteria were selected and introduced to the researcher. The participants who were volunteers from the WA AIDS Council were arranged by a senior staff member of the center.

Sixteen people who met the criteria were invited to participate in the study at different times. The time of invitation was considered in relation to their readiness. However, the health status of these participants was a main concern, particularly their mental health. The researcher used telephone and individual contact to provide the information related to the study in the first instance. This included the purpose of the study, method of collecting information, estimated time of involvement, and benefits of the study. An individual meeting with each participant was then arranged and performed. The participant's willingness to take part in the study was reconfirmed before the consent form was signed. However, before arranging the interview, three people withdrew themselves from the project, owing to the participants' inability to cope with the emotional stress caused by the illness. One participant was excluded after the interview was partially carried out due to the participant experiencing drowsiness during the interviewing period. A total of 12 people was the final number of participants included in this study. Two people participated in the pilot study and 10 were volunteers for the main study.

Once the consent form (see Appendix A) was signed, the first participant was individually interviewed for approximately one and a half hours in a single room and without interruption. All interviewed descriptions were recorded by audiotape. The participant chose to be interviewed at the center where it was more convenient for him. The second participant was asked to write down his lived experience after having HIV infection. The data from this part was not analysed in the main part of this study and the two informants did not participate in the second stage of the study.

In the second stage of the study, 10 participants were interviewed in depth. The data was obtained from those selected participants by audiotaped interviews and from the researcher's observations as recorded in field notes. The process of data collection in this study was suggested by Drew (1986) and Morse (1991). Drew (1986) suggested that in a phenomenological study, participants' own experiences were considered as data and were examined within the context of the study. Similarly, Morse (1991) reported that the interviewer was seen as a research tool that was a main instrument in data collection.

Consistent with phenomenological methods, open-ended questions were used to initiate the interview. Unlike structured conversations, the open-ended interview was the engaging in co-operative dialogue that built a trusting relationship between the researcher and the participants (Knaak, 1984). The following question was asked; "Please describe your experiences since you were diagnosed having HIV/AIDS." The participants were then asked to describe all thoughts, perceptions, and behaviours they could recall about their experiences since being diagnosed with HIV/AIDS.

Awareness of the researcher's biases, presuppositions, and experiential knowledge were acknowledged prior to each interview and set aside during the data analysis. No attempt was made to influence the

participants' descriptions, so that each description was clearly the participant's perspective of the phenomenon of concern. This bracketing was done in order to capture and distinguish empirical reality outside the researcher's views (Swanson-Kauffman & Schonwald, 1988) and to depict accurately the reality described by the participants (Beck, 1992).

During the interviews, the researcher viewed herself as a research tool and used the technique of intuition, reduction and bracketing. She avoided all criticism, evaluation, or opinion. Strict attention was also paid to the phenomenon under investigation as it was being described. The technique of reduction, by concentration on the phenomenon, became absorbing. At the same time, bracketing was utilised. The purest description of the phenomenon under investigation was obtained. The data was then truly comprehensive with accurate interpretation of what was meant in a particular description.

Observation of each participant's behaviour during his/her interview was spot-noted by the researcher. The field notes were recorded to support the observation of the participants' behaviours and their interactions. Spot-note taking was helpful where non-verbal communication occurred. Using both techniques served as a way of triangulating the data sources and enhanced claims for validity (Kimchi, Polivka & Stevenson, 1991).

All interviews and observations were conducted and collated by the researcher. The time for interviews ranged from 45 minutes to 1 hour and 45 minutes. At the end of each interview, demographic information, such as age, educational background, risk factors related to HIV infection and length of time after being diagnosed HIV infection, were verbally collected.

Data Analysis

In this step, any information from the pilot study was not taken into account. Data analysis was done concurrently with the data collection from the time of the first interview. The transcription of each participant's

experiences was analysed using Colaizzi's (1978) method because evidence of validity check was contained in the methodology (Drew, 1986; Haase, 1987). The method consisted of the following six steps:

1. All taped interviews were transcribed verbatim by a professional typist. The researcher then verified the completeness of the written transcripts by listening to each audiotape. Any incomplete or incorrect part was added or edited. Listening to the audiotapes was then reviewed with the gathering of information from the spot-notes taken of observation during the interviews.

2. The researcher read the written transcript of each participant in the main study several times to acquire a feeling for the content and to arrive at a global analysis. Significant statements and phrases of each transcript which directly pertained to the experiences of those living with HIV infection were extracted and coded to capture the lived meanings of the participants' experiences. If any further inquiry relating to the descriptions of each participant was required, a second interview or written questionings were submitted to the participants. The information requested was then analysed. During the study, a second interview was conducted with two participants. One participant required written questions to be provided by the researcher.

3. Meanings from the significant statements and phrases from the interview with the first participant in the main study were formulated and organised into themes. The thematic descriptions were then clustered from the aggregation of the formulated meanings.

4. The third step was then repeated for the remaining participants' transcriptions. The emergent themes that were common to all of the participants' descriptions were subsequently organised by comparing each participant's transcript with those of the others. Themes that emerged, after analysing each new transcript, were then added to the categories of themes

already identified from the previous interviews. The saturation of data, which signified completion of data collection, had been achieved when no new categories of themes could be identified.

5. The results of the data analysis were integrated into an exhaustive description of human experiences of living with HIV infection. The data yielded 24 themes in the first instance and these were subsequently collapsed to six essential themes.

6. The exhaustive descriptions were returned to the participants for validation of the original experience. Any new relevant data was incorporated into the fundamental structure of the experience.

Content validity

Although reliability of this study was unable to be tested, the validity was verified concurrently with data analysis. Several techniques for determining reliability and validity in qualitative research have been discussed by several researchers (Beck, 1992; Kahn, 1993; Miles & Huberman, 1984; Sandelowski, 1986). In this study, specific procedures were taken to address criteria of credibility, fittingness, and auditability (Sandelowski, 1986).

The credibility of the researcher's interpretations of the data was enhanced by participants' verification and nurse researcher checks of the transcripts and the exhaustive descriptions. Each participant was asked to read a copy of a taped transcript and asked whether s/he recognised the experience as their own. Any additions, deletions, and corrections were invited. Minor corrections about philosophical belief was requested by one participant. The descriptions, emergent themes and steps in the analysis were also shared with two experienced nurse researchers who were the researcher's supervisors.

Fittingness or transferability of the study refers to the probability that the research findings have meaning to others in similar situations

(Streubert & Carpenter, 1995). In this study, how well the findings fit outside the situations was verified by two participants who not only had experienced the phenomenon under study but who were able to articulate their experiences. The participants reviewed a summary of the exhaustive description analysed and agreed that the description was suitable to their experiences. This member check was suggested by Guba and Lincoln (1985).

Auditability is suggested as a criterion for evaluating the consistency of qualitative findings and another researcher is able to follow the methods and conclusion of the original researcher (Beck, 1992; Sandelowski, 1986). In this case, the theme clusters were explained with examples to clarify the transition of formulated meanings to theme clusters.

Artistic rather than scientific approaches were used to illustrate the findings. This served to acknowledge what already existed rather than presenting a facade of objectivity and emphasised what actually emerged from the data (Sandelowski, 1986).

Ethical considerations

Permission to conduct the study was obtained from the Western Australian AIDS Council, the AIDS Pastoral Care groups and the Edith Cowan University Ethics Committee before proceeding with the study. Each participant involved in the study participated on a strictly voluntary basis. Those people who agreed to participate were informed of the confidential nature of the study. Prior to commencement of the interview, informed consent (see Appendix A) was obtained from each participant. Expectations for participation and assurance of protection of their rights were included.

To provide maximum assurance of anonymity and rights of privacy, only the participant's first name was written on the consent form. Each

participant was assured that s/he would be able to withdraw from the study at anytime without conditions or harmful consequences.

The researcher also prevented any emotional distress which might develop in relation to recalling negative memory. To enable this the researcher maintained awareness of any possibility that might affect the participant's emotional balance during the interview. The participants' behaviour was continuously monitored by observation. In addition, professional counsellors based at the support groups were promptly available by mutual arrangement, to support those who became distressed. No participant expressed emotional distress during the interviews conducted and no professional counselling was subsequently requested.

After termination of the study, the audiotapes were transcribed verbatim. All tapes will be erased on completion of the study. Pseudonyms and code numbers were assigned to the transcriptions to protect the identity of the participants. All records are and will remain securely stored in the researcher's locked safe. After preservation of the data for five years, the records will be destroyed.

CHAPTER FOUR

Findings

The Participants

Eight men and two women who were HIV infected participated in this main study. The participants ranged in age from 30 to 69 years. All participants were Australian permanent residents for at least six years or more. Seven people were Australian born. The ethnic backgrounds of others in the study were Brazilian, Spanish, and Austrian. Each participant revealed that they were raised Christian.

Although all participants were not asked specifically about their sexual orientation and risk behaviours, information revealed during the interview indicated that the men were homosexual and the women were heterosexual. Both women experienced intravenous drug use and one was a sex worker. The length of time since HIV-positive diagnosis varied from 3 years to 14 years. Four participants identified their HIV status as asymptomatic HIV. Symptomatic HIV infections had developed in the others. Three participants were unemployed before being diagnosed HIV positive. During each participant's involvement in the study, three were in full-time employment and seven participants were disabled pensioners.

The Experiences of Living with HIV Infection

The taped interviews of the participants were transcribed verbatim. Meanings were then formulated for each statement. Several readings of the transcriptions yielded 24 significant themes which were clustered into six major groups. These included social discrimination, emotional disturbances, changes, losses, suicidal attempts, and dealing with difficulties for surviving. Numerical suffixes at the completion of each participant quote directs the reader to the distribution of the data.

Social discrimination

Many participants viewed AIDS as a "social stigma" and frequently experienced prejudice and discrimination. These people used the phrases "being judged", "cut off", and "people don't want to hear about HIV" to characterise the feelings of prejudice and discrimination. A woman, who was an intravenous drug user, felt that she was socially stigmatised as a result of being infected with HIV.

"It's just that a lot of people judge you and put you down and they put you in a category where everyone gets treated the same. It's like you're blacklisted for life almost." (4)

The people perceived rejections from various sources including family, partners, friends, colleagues, health care workers, and society in general. More than one source of rejection was experienced.

A man and his twin brother experienced being rejected from their parents because they both had an HIV infection.

"Now my mum and dad don't know very much about the virus and they won't listen to us (the participant and his brother who is dying from AIDS)." (6)

Two people talked about the disruption of relationships between partners that actually happened after disclosure of the HIV infection. One man experienced rejection from his three former partners when he attempted to tell them about his HIV infection.

"To put it in context, the first one screamed and ran away, the second one screamed and leapt out of the window, naked from a first floor flat window and broke his leg on the fall - as I told him, 'you would have been safer with me'. The third one just said, 'Mm mm, I have to think about this,' walked out and I have never seen or heard of him again." (9)

Another man described his sexual identity as homosexual, but he had attempted to be heterosexual by living with his girlfriend. However, their relationship was shattered immediately after he told her he was HIV infected.

"I was told on Friday. She left me that night. She left me. She took my daughter away from me."(6)

In the beginning, some people did not sense that they were rejected by others because the reaction of keeping away from them was subtle and covert. One man prepared for a party, but no invited friends came to join him.

"One day I cooked a dinner and then I invited this group of people (his friends) to eat. They didn't come. They all had an excuse not to come." (1)

One woman, who had been diagnosed with HIV infection for almost eight years, experienced direct overt social rejection on many occasions. She had three children, two sons, and one daughter. One of her sons was HIV positive. After she was diagnosed with the HIV infection, she discovered she was pregnant with her daughter, who was subsequently tested as HIV seronegative. Her boyfriend, who knew about her HIV status before having a sexual relationship with her, left her after she gave birth to their daughter because he felt fear of contagion. She sensed that her boyfriend and people in general were panic stricken, over anxious, and fearful of her.

"I wasn't even allowed into certain shops and I was so scared to walk out of a shop because there were people waiting for me, I had to call a taxi and get a taxi home - that happened quite often. So I moved out of that suburb."(4)

Her son, who was HIV infected, was also involved in the issue of social rejection. The employee of a pharmacy forced her to leave the toddler outside the store because he was HIV positive.

"She said, 'I don't want that boy in the shop, he'll spit on everything.' Scared that the virus was going to come through spitting or if he touched a toy or something like that."(4)

Even her neighbours sold their house to move away from her.

"They said that the AIDS virus was going to come up through the drainpipes and through the gutters under the fence."(4)

Another man felt that everyone knew about his HIV status. He sensed he was covertly discriminated against when he bought a drink and the waiter feared contagion from him.

"I've got one guy at the... (hotel), who every time I buy a beer will not give me a new glass. He uses the same glass. Everyone else gets a new glass. I get the same glass. People don't realise he's doing it, but I know it's going on. I've seen it." (6)

Aggressive and life-threatening reactions were also experienced. A man was threatened after his partner died from AIDS and his partner's mother claimed that the house he lived in belonged to her.

"I've had my house ransacked and I had graffiti sprayed all over my car and the front of my house. Yes, basically telling me to go away and die. That was very frightening, very frightening."(3)

News media were blamed for evoking fears of HIV transmission. Several people complained that the media projected a negative image to the public, encouraging negative attitudes towards them. The people were categorised similar to people with other contagious diseases, such as leprosy and plague, which needed to be isolated.

"People were saying you should be locked up on an island somewhere. People were comparing us with lepers and saying you know, that you need to lock us away and that you shouldn't have sex and you shouldn't have rights to have any sex, or have any children."(10)

Social attitudes towards homosexual men also had implications to the negative reactions towards people with HIV infection. Several study participants who were homosexual were called "faggot", "poofter" or "queer." They perceived that being homosexual and HIV infected were both social stigmas and combined with each other.

"Because there's a lot of people out there, if you tell them that you're either gay, or you've got HIV - [you are] very very stereotyped." (9)

"They said, 'AIDS is poofster spread'." (6)

In addition, when a man told others about his HIV status, it was like he was telling them about his sexual identity.

"That is also a clue to the fact that I am a homosexual. Somebody reacted badly, but they don't react because of HIV you know. They react because they said 'Ah! if he has HIV, he must be gay' you know. They react because I'm gay." (1)

The experiences of being rejected by others in relation to the combination of being homosexual and being HIV infected was described as "a double whammy". It had led a man to the alienation of his family.

"They've always said that to us and they turned round and said, they don't like poofsters and they definitely don't want us to be anywhere near them because we have AIDS and we might give it to them." (6)

The rejections were also experienced from a group of religious people. One man always participated in religious activity such as attending church regularly. After his HIV status was disclosed, he was refused admission to a religious order.

"It was as though they were afraid that I would infect the whole Order." (2)

Another man, who was rejected by his family because of being homosexual and HIV infected, sought out religious support. Initially the people in a church performed a warm welcome for him. However, after he told them about his HIV status, he was viewed as a "sinner" who needed punishment and was asked to leave the church.

"I was actually asked to get up and leave. Because people would not go to the church any more, because I had AIDS. They turned round and said that I was a sinner, that I belong to the devil, because I am a homosexual. This (being HIV infected) is my punishment." (6)

Negative reactions amongst people in the homosexual community were also experienced. They were viewed as people who had "poor practices."

"Amongst gay males, if you were diagnosed HIV, you were automatically basically considered stupid. Because we knew about it, as gay males. And it was around. So why did you put yourself at risk and catch it?" (9)

One man sensed that he was classified as "low standard" amongst others in the homosexual community after his illness worsened and he became unemployed.

"They don't like the people who cannot be of their standard, cannot behave like them. If you cannot be in their standards you know you are no good. You will find that people will ignore you, people don't want anything to do with you if you're different. Because you're different they will treat you different." (1)

The man also sensed that those people rejected him because he reminded them about their risky sexual behaviour.

"They don't want to hear from you because I guess they are very scared of HIV. And it could happen to them. So they preferred to forget everything. And if they see a guy with HIV you know, they are going to be reminded all the time." (1)

Several people talked about the experiences of being rejected by the health care workers, when they visited hospital. One was told of his HIV positivity, while he was hospitalized for hepatitis.

"I'll never forget how I was told of having the virus. The registered nurse came into my room and said 'You have AIDS.' and walked straight out of the room." (2)

Reluctance and spending less time being cared for, were perceived as health carers' reactions of rejection.

"There were two or three nurses who were very scared to go into my room because there was no point in inspecting." (1)

Being cared for by people who had harsh or apathetic behaviours were also included in the sense of being rejected by the health care workers.

"I feel like I'm getting put down a lot when I'm in the hospital and some of the doctors aren't very nice, they're very rough and very mean. They haven't got the right to treat anybody like that." (4)

One woman felt unclean when she noticed a few nurses wearing many unnecessary protective garments while they were caring for her.

"Well just like putting the side of the bed up, you can't get HIV. It just made you feel so dirty and disgusting. You can't infect somebody just from lying in a bed. It's like why do you have to treat me like this." (10)

However, some people accepted that those mannerisms were important to protect health carers from HIV transmission.

"I could see it in how they treat you because when they (the health care workers) came in with gloves and so on, but I didn't bother. It doesn't make any difference. They have to be protected." (7)

The rejections perceived subsided over time and were alleviated by the long-term relationships with those medical carers who had rejected them in the beginning. The man who received harsh behaviour from a physiotherapist was able to sense the changed approach.

"At the end she was very good with me you know. Now when I go to ... (hospital), the doctor told me she asked how I am. They have all changed in the end." (1)

In addition, some admired the family-like approach.

"Even the nurses, they're all nice. They will talk to you - the nurses and the social workers they're like family - they treat you like family." (7)

Emotional disturbances

People expressed a variety of emotional disturbances which occurred in their day to day living. One man viewed that people infected with HIV were "in and out" of an "emotional cycle" which was disturbing and

continued indefinitely. The cycle started following being diagnosed with an HIV infection.

"You get cyclic things of anger and depression and worry and then you cycle out of that and into 'this isn't so bad, this is fine, I can do this. I'm living. I got my health'. And then something will trip it and you'll start cycling back down through it. Then you start cycling back up out of it, so there is this constant cycle you are going through it." (9)

The emotional disturbances most commonly experienced were fear related to death and dying, confusion, anger, uncertainty, guilt, and loneliness.

Fear related to death and dying. The experience of living with dying began when learning one's diagnosis was seropositive for HIV infection. Many people viewed that being told by physicians that they had HIV infection was like receiving "a death sentence". When asked how they felt after being diagnosed HIV positive, the terms "shocked", "scared", or "horrible" were repeatedly expressed.

Four people, who were tested for the HIV antibody without their consent and without being counselled, experienced fear of dying. One man was "shocked" when his sperm count check became a "death sentence". He was told he was HIV positive.

"They said, you're positive. I thought, 'Oh! great, I can have kids'. And I went away thinking really happy and then I saw a lady. She said, 'oh, have you had an AIDS test?' I said, 'no.' She said, 'well, we've got it on our records that you have.' I said, 'I never asked for one.' And she said, 'well, you're positive.' I said, 'what do you mean I'm positive?' She said, 'well, you've got it.' I said, 'no, I didn't want an AIDS test, I wanted to see if I could have children.' And they told me I've got HIV and I don't know if I can have children. So I found out something I didn't want to know." (6)

The others, who consented about their HIV tests, also felt a fear of dying. One man viewed people diagnosed with HIV infection as the individuals who have "stopped being active vibrant human beings" and

become "worry machines". He refused to collect the result of his first HIV test.

"I didn't collect the result. I was tested, but I didn't go back for the result. I was afraid. Afraid of being told-yes that I was HIV positive." (9)

After meeting with her physician, a mother kept awakening before sun rise to continue living for her children when she felt fear of dying from AIDS.

"I asked him (her physician) 'When will I die?' and he said, 'Well, one morning you just won't wake up.' So in the back of my head over the years, I've had this thing. Well if I don't go to sleep, I'll still be alive. So I start not going to sleep. Staying awake all night until the sun gets up in the morning." (4)

The fear of dying is also related to the severity of an HIV illness. Many people felt that death was in the near future, especially when illnesses developed or became worse. One man stated,

"Everytime I go to the doctor and I'm sitting there and he (his doctor) goes, '...(Participant's name), you've got this problem now, or you've got this', and you sit there and think, Shit! I'm dying quicker. I'm closer to death. It's really scary." (6)

Another man felt fear of dying related to the stage of his illness when he was diagnosed with HIV infection. He was diagnosed as HIV negative for four years due to the misspelling of his surname, even though the test result was positive. The result of his HIV test was reviewed after he developed *Pneumocystis carinii* pneumonia. He sensed that the delayed diagnosis caused him to be late for the HIV treatment.

"And when I got sick and they went back through the records and that I'd been positive since then. That I knew I was going to die and I think I was more scared because it was four years - I'd been positive for four years and hadn't had any treatment or nothing had been looked at. It was very scary" (3)

Many people talked about their experiences of witnessing the death of their significant others from AIDS. They perceived that watching those who were dying from the same illness was an extremely traumatic life event. It heightened the feelings of fear of the process of dying.

"When you see someone dying it's like you're virtually seeing your own death." (3)

"It hurts because you sit there and you see your friends dying and you see half of them losing weight, or some of them looking really skinny or some of them with Kaposi's black spots all over them and you sit there looking at them get really sick. Then you think, 'I've got the same virus as them, am I going to die like that?' It scares you." (6)

The fear of dying also increased if whom they had seen dying was a sibling. Two men who were one half of two sets of identical twins had experienced caring for their twin brothers. One had died of AIDS and the other was in the terminal stage of AIDS. One man from one set of twins expressed his fear of dying when he cared for his twin brother.

"Watching him get sick is like watching myself getting sick-it's like looking into a mirror, it's very very scary." (6)

However, the people in the study sensed that they were afraid of the process of dying rather than fearing death. The suffering of pain and being bed ridden were two examples of this fear.

"I'm not scared of death any more, but I'm scared of dying. I'm scared of pain. Pain is the thing that I'm scared of." (3)

"Frightened of dying poorly, frightened of dying ugly. You know that gaunt grey look with somebody having to bathe me, somebody having to change my kimbies because of incontinence, rolling over in bed so that they could straighten it, all the rest of that - that frightened me." (9)

The twins also expressed their fears of dying alone. The first twin had no living relatives. Only his twin brother and his partner were his significant

persons, and both had recently died from AIDS. His concern was about who would care for him when he was in the terminal stages of the illness.

"I was there to hold his hand (his partner's hand), but he wasn't going to be there to hold mine. Who's gonna hold my hand, when I die?" (3)

Not only did the second twin have a fear of dying alone, he also felt that he was too young to die.

"Everyone is dying - yes, we all know. We sit there and think we're going to die at the age of 100 years old, we're all going to die old people. I'm 33 years old and I'm dying. I don't know how long I've got left. Being told that you're going to die a lot earlier is very very scary." (6)

In contrast, the oldest participant in the study, who was diagnosed asymptomatic HIV positive fourteen years ago, revealed that being diagnosed with the HIV infection did not cause him to feel any fear of dying. He said, "I'm old enough." Apart from having an HIV infection, however, he was a diabetic. He perceived having diabetes more severe and more important than being aware of the HIV infection.

Confusion. Four people described the experience of confusion in different ways. One reported that he always practised safe sex. He disbelieved in the diagnosis and felt confused when he was diagnosed as HIV positive.

"Confused, like everyone else. Why me? Because I always practise safe sex." (8)

Another man felt confused when he developed lethargy not realising what was happening to him.

"I just get confused because I like researching. I like studying. So as the symptoms come first I don't have a chance to go out and study or to inquire with doctors to clarify it." (5)

The others' experiences of confusion were in relation to how they dealt with the diagnosis of HIV infection and what their future life would be like for them.

"I don't know what to say. I didn't know who to tell, or how to tell, or if I should tell." (3)

"More confusion of what possibility lay ahead because even then it was still early and not talked about (AIDS) as much as it is today." (5)

Anger. Feelings of anger related to the HIV infection were experienced by several people. The feelings of anger were more likely to be related to the HIV infection and the resultant negative social reaction.

When a man was first diagnosed with HIV infection, he felt anger toward the person who infected him with HIV, without knowing the identity of the person.

"It made me angry, the person who gave it to me. I don't know where I got it from, but I was very angry with everyone." (6)

Another man felt angry with the diagnosis of HIV infection. Being an HIV infected person was hurtful. He sensed that his life span would be shortened.

"I got angry at being an infected person, not at the death side of it. I hadn't yet reached that particular mind set. I got angry at the potential waste, the things that I could have offered to whoever, wherever and were going to be wasted, that the time's cut short." (9)

A woman felt angry with the HIV infection that caused the death of her close friend and others.

"Yes, I was really pissed off. Like it was also around at a time when a lot of my friends were dying. And it's anger about the disease, anger about young people dying. I was angry and I thought, why her?" (10)

The others felt anger when they perceived being "cut away" by their friends. A man cried when he felt angry with the situation of being rejected and discriminated.

"Angry with what people say and people's attitude. I'm human, I've got a heart and I can cry as well and having people sit there calling me faggot, queer, you dirty slimy AIDS thing." (6)

Another man felt "betrayed" when one of his friends disclosed his HIV status to others. As a result of the disclosure, he was immediately rejected by other people with whom he came in contact.

"I thought they had betrayed me because I said something to him in confidence and he had broken that confidence without telling me." (1)

The anger was sometimes physically and aggressively expressed.

"I hit a nurse because she grabbed hold of me and tried to tell me what to do, because I was very angry with everybody - leave me alone, I've got the virus, I'm dying." (6)

Uncertainty. Once the people were diagnosed with HIV infection, they actually asked their physicians "When will I die?" (4) or "How long have I got to live?" (8)

They were unable to predict their term of illness and wellness.

"And when you see one of your friends die, you think, shit, this is going to happen to me, but when? You know it's going to happen, but how are you going to die?" (10)

When being HIV infected was considered having a fatal infection, some people mentioned that their future was beyond their imagination.

"I don't know what is going to happen later." (1)

Their future might not be planned.

"How far do you plan for your future?" (10)

Living with uncertainty implicated one man's career prospects. He felt uncertain about his career when he was first diagnosed with the HIV infection. He felt he might be dismissed if the illness worsened.

"What happens when you get sick? Do you still have a job because no-one's going to give you a job if you go to work for 6 weeks and then off to hospital for 3 weeks?" (6)

Guilt. Several people felt guilty about issues that were mainly related to the HIV transmission. A woman felt guilty about those with whom she had shared her needles and syringes. She also felt guilty about her son because she infected him with the HIV.

"Because I was breast feeding him and that's maybe why he definitely got it. If I'd known that, I wouldn't have breast fed him." (4)

A man blamed himself that he put himself at risk of HIV infection by practising unsafe sex.

"Any anger is directed to myself for being so blasé in thinking that I could never get the virus so I did not take any safety measures." (2)

Loneliness. A few people expressed feelings of loneliness when they talked about their expectation of social contacts and the realities of being rejected by society in general. A man who had full blown AIDS for eight and one half years sensed that he had to confront multiple losses and changes for such a long time. No one could understand his feeling of loneliness.

"It became very very lonely. It's like your whole lifestyle changes - your eating habits. You honestly lose so many friends - your life changes, it's as if you're born again. Even though I've got a boyfriend, you still think that they don't understand because they don't have what you've got. They don't wake up in the middle of the night. They're not the ones with night sweats. They're not the ones that have got to take tablets. They're not the ones poohing their beds. They don't know what it's like." (6)

The feelings of loneliness also occurred when a significant person who did understand these people was absent. One man rang his carer at one o'clock in the morning and cried after his sister who visited him for a holiday went back home to another state. He was alone again.

"I missed her (his sister) very much when she went home. I had a few drinks to compensate for my loneliness. Also I thought I might never see her again as I didn't know what my chances of survival were going to be." (2)

Another man felt lonely when his relationships with friends changed due to his HIV status.

"It hurt. It's very hard. It hurts. Because one day they're there and you can ring them up and talk to them about just about anything and the next day they don't want to know you. All of a sudden all of that stopped and I was at home all the time on my own. That's not easy to take. You get very lonely." (3)

In the broadest sense, feelings of loneliness were expressed in terms of "being lonely among others" rather than being alone.

"Sometimes you feel like you're the only one on the planet, I feel like sometimes - I feel like I'm the only one that can speak English and everyone speaks another language. Yes, being lonely you feel like no-one understands you." (6)

"It just felt like you were all alone in the world. It felt like all the world is happening out there and you're by yourself and you're cut off from everyone." (4)

When asked what it was like being lonely and alone, one man said:

"It's horrible. It's empty. There's nothing to look forward to. You wake up. You get up. You have a cup of coffee and it's like wondering what you can do. You just find that you're on your own all of a sudden and like what to do?" (3)

Changes

The experiences of change included physical changes, lifestyle changes, sexual behaviour changes, and attitudes towards self changes. The forms of the changes were both positive and negative.

Physical changes. People who developed illnesses related to HIV infection experienced several changes of physical appearance and functions.

"A lot of little things started to happen, like a fungal infection in my mouth and bottom, shooting pains. So they were mild stuff but I started to think you know it's now time, a stage that the body's not the same any more." (5)

A man who was a long term survivor explained his greatest change related to his physical function. His physical appearance was also included in the change process.

"I've just been told I've got TB'. I've got KS (Kaposi sarcoma), TB (Tuberculosis), HepB (Hepatitis B), PCP (Pneumocystis carinii pneumonia). I've got diarrhoea. I've got weight loss. I've got headaches. All my teeth started getting wobbly from the HIV virus, I ended up getting gum problems. On my 30th birthday, my teeth fell out on my birthday. And I woke up and I had no teeth and I had blood everywhere." (6)

Some changes were temporary, but some were permanent. A man developed muscle weakness and became disabled as a consequence of meningitis.

"It attacked my nervous system. My legs and arms weren't working properly."(1)

Three men experienced physical changes as a result of the adverse side effects of the medication taken. The men experienced hypotension and dizziness. One of these men had four falls and experienced a head injury as a result of hypotension related to the side effects of the medicine taken.

"My blood pressure dropped so much. I was not allowed to walk and had to wear special stockings to help the blood supply be as it should be. Unfortunately I had four falls, one resulting in my having eight stitches to my forehead." (2)

Lifestyle changes. The people in the study perceived that the HIV infection had a profound effect on their day to day living. One man's

lifestyle changed from being an active young man to being a patient who frequently visited the hospital. He then decided to resign from his work.

"Before I used to work in the mine, and with HIV you have to be close to the hospital and things like that. So it did affect my job and I had to leave it and do something else."
(1)

For some people who became ill, most of their time was spent at home.

"The body is really feeling pretty old all the time, like the body of an elderly person. So lethargy, yes, has been the main problem. I used to be very active, getting up early, doing exercise regularly. It has been two years since I haven't done it. One day it's really energised, I go and I do it and then the other day you don't want to lift your arm. It's so slow and that's the way it goes, lethargy." (5)

The man who developed meningitis and muscle weakness related to HIV infection reported that his lifestyle was totally changed. His activities were mostly performed while in his wheelchair.

"I was on my own. I could cook and do all things, and do the cleaning of the house because from a wheelchair you cannot clean a house very well. Before I used to go out quite often. I go to party and dm...spending money to all those things. Now I don't, you know. I don't go out." (1)

The adverse side effects of medication taken also affected the lifestyle of another man when he was on anti-depressive drugs.

"I had a car. I'm not allowed to drive no more because of my medication. So I'm now on my feet and public transport, so I can't drive."(6)

In addition, financial insufficiency was perceived as a major cause of lifestyle changes. Several people were not able to work when their illness from HIV developed. A man reported his whole lifestyle had changed when he decided to prematurely resign from his career. Being an unemployed person with symptomatic HIV infection, he had to limit his recreational activities and leisure time.

"You can't go. I mean you can't spend any money in the leisure. And you have to really count any payment. It all changed very quickly. I had to quit work. Everything was uprooted all at once. That made things very difficult. I can't afford just to get up and go out to a restaurant. I can't afford to get up and go away on holidays and things. I only get the basic pension and it still costs the same to run the house now as it did then, even though there's only one person. I couldn't get out in the garden - just the normal every day things we used to do. All that changed." (3)

However, two people experienced positive lifestyles changes after their HIV status was disclosed. One man, who was unemployed before being diagnosed HIV infection, talked about his dissatisfaction with life before being diagnosed with an HIV infection as follows:

"I was a middle-aged homosexual male. I was unemployed. I was facing unemployability. I was unhappy with that. I kept worrying whether I would ever be employed, whether I could actually get a job, use the degrees I had and start functioning as a human being, but instead, all I'd ever do was drink. I would sit and drink day after day. Basically I put my life in a toilet and started to pull the chain after me. So that was what life was like before the infection." (9)

Since involvement with the community AIDS support groups, however, this man had gained employment as an AIDS support group worker. His lifestyle became socially active.

"I work primarily with the general community, but I have also worked with the HIV specific. I have worked on projects for the HIV positive people, the HIV positive community." (9)

Sexual behaviour changes. All people in the study realised that to be sexually active could transmit the infection to their partners. One of them perceived that sexual thoughts were "the worst enemy" that each had to struggle with when becoming an HIV infected person. Another man redetermined his sexual behaviour after being diagnosed with the HIV infection so as not to transmit such a harmful infection to others.

"I had to decide whether I would remain sexually active or not." (2)

For one man, he realised how his sexual behaviour was risky. He did not want to place his lover at risk of contagion. As a consequence, he and his lover reverted to an asexual relationship. However, the lack of intimacy in their sexual relationship added emotional distress.

"Our sex life is very very boring, certain things that gay people do. I can't make love to him (his lover). I can't kiss him because I have thrush in my mouth and my throat. I don't want him to get it, so I can't kiss him. In a gay relationship, I can't do that." (6)

Nonetheless, many people in the study placed sexual behaviour in lower rank of importance when compared with the psychological intimacy of a relationship and the sharing involved. A woman stopped having a sexual relationship after her boyfriend left her with their daughter.

"I don't have any. I don't need a sexual relationship. I just need someone to wake up in the morning with, a bit of a cuddle, for me just to have someone there." (4)

Eight people stopped engaging in sexual behaviours by adopting a celibate lifestyle. The majority practised celibacy after being diagnosed with the HIV infection. Some of these people were practising celibacy permanently whereas the others were initially celibate and recommenced having a sexual relationship with others later.

One man practised celibacy because he felt unclean in himself. He described himself like "a walking bag of disease waiting to happen on someone else".

Others practised celibacy permanently to protect others from an HIV infection.

"I don't want to put anybody else at risk with this virus, so it's the best not to do it. It doesn't even go through my head any more. I couldn't live with myself if I thought

that I would pass this on to someone else. Sex is forget it. Not worth it." (3)

"It is something I could send somebody to their death with. I mean I'm thinking about sex, but I'm not practice (having sexual relationship with others). "(7)

Some people chose to stop having sexual relationships with others because they did not know how to deal with them. One woman in the study always succeeded in convincing her casual partners to practise safe sex. However, when the relationship became closer, she chose not to continue the relationship and temporarily practised celibacy. She did not know how to deal with the closer relationship.

"They want to see me a couple of times and then it's like a week, two weeks, now what are you going to do. You've been having sex with them or whatever and then you think, shit, now what do I do now, so what I'd do is break off the relationship rather than go on because then it gets complicated." (10)

Being homosexual also implicated the need for celibate practise. One man wished not to be a homosexual and did not want to have a homosexual relationship with his partners. He thought about practising celibacy many times. He was able to practise celibacy after being diagnosed with the HIV. He said his celibate practise was not related to the HIV infection.

"Because I know already how good I was and I know already how bad I felt about having an addiction to sex and that kind of thing." (5)

When asked what it was like being celibate, one man expressed losses of sentimental intimacy, sharing, and companionship.

"Boring...There's no interaction with a human being, not on that intimate level. One can masturbate until the cows come home, if you have that much stamina. I don't, but there's no intimacy. There's no warmth of another body, there's no sign of another breathing. You wake up alone and you go to sleep alone and you know that that is how your life is going to be - boring, boring, boring." (9)

Attitudes towards self changes. Being an HIV infected person led several people to change their attitudes towards themselves. The perception that he was like a "walking bag of disease," a man felt changes about his attitude toward himself.

"I felt unclean. I felt diseased. I felt unclean personally."(9)

An individual's self-respect was affected when the people experienced social rejection.

"You have to be somebody else, almost somebody else. You know, the rest of your community, the rest of your friends, they have negative attitudes towards you. You are not the same for them."(1)

Individual image of self also changed. A man was concerned about the change in his deteriorating physical image. He sensed that he was not attractive to others as he had previously been in the homosexual community.

"Before I used to be a very happy go lucky person. People used to say, if you go to a party take ...(participant), he's a laugh. I make people laugh and everything. I used to have beautiful teeth. I used to have a big chest and everything. I won't shower with ... (his partner) any more. I won't go to the beach any more. (6)

The diagnosis of HIV infection also influences an individual's self-esteem. A man sensed that he had low self-esteem because of being homosexual, and his self-esteem was lower when it was in conjunction with being HIV infected.

"My self-esteem could get rather low when I was diagnosed HIV. It seemed to confirm what I felt about myself." (2)

However, two people sensed that their self-esteem increased. One woman reported that she was able to identify with a changed lifestyle and needs after receiving counselling and professional support following

diagnosis with the HIV infection. Working with the AIDS support group was considered a major factor that increased her self esteem.

"Like when I was first diagnosed [with HIV], it (her self esteem rating) would be minus 10. Now I guess it would only be about 7 out of 10 privately. Professionally I have very good self-esteem. I'd give myself 9 out 10, professionally in this work." (10)

Losses

People experienced multiple losses related to HIV infection. The information revealed that losses relating to HIV infection of the people with HIV in this study encompassed loss of relationships, loss of significant others, loss of employment, and loss of opportunity to do several things.

The people sensed that their relationships with their families, lovers, friends, and colleagues were lost, since they were "cut away" by those who feared contagion. A man used the word "divorced" when he talked about his relationship with his family. He had tried to disclose his HIV status to his mother for several years, but his siblings would not allow him to do it.

"This was not a group of people that I particularly want to be with. I was trying to get my mother to a headspace so that I could tell her (Telling that he has HIV infection). But I had to beat my way through my sister and my brother. Eventually, I don't want to do it any more. " (9)

Several people also experienced loss of their significant others who died from AIDS. The significant others included their family members, lovers, and friends. One woman developed a mutual relationship with a friend whom she first met at the AIDS clinic. Her friend later died from AIDS. She felt that it was pointless to her to develop friendships with others.

"I'm sick of making friends with someone and then they die a year or two years later. What's the point in becoming friends with them?" (10)

The people also experienced a loss of career. Being rejected by colleagues was perceived as an intolerable situation. A man left his job and refused to continue his relationship with his family after his sister disclosed his HIV status to his colleagues in his workplace.

"No-one at work knew. I'd kept it very quiet. I was happy - I quite enjoyed the job. I felt like a normal working person. And my sister walked into my work one day and just shouted out, 'Hey faggot, have you told everyone you've got AIDS?' Messes up the job. And turned round and all my friends at work were looking at me and I felt like half an inch tall. I just got up and walked out and left ...(his workplace) and have never seen my family since that time." (6)

Another man decided not to apply for his new career when his symptoms became worse.

"I didn't want to apply for jobs knowing that I'm going to have the days with lethargy and I have to knock off work." (5)

As a health care worker, one man had to resign from his work. His physical and psychological health made him unqualified to care for other patients in hospital.

"When I had my Commonwealth Medical examination, I had a very bad chest infection. The Medical officer said in all fairness that she could not send me back to work. There was also the fact that I was learning to cope with being HIV infected. I could not give 100 per cent of myself to my patients. I've had to get used to the fact that I could not work at my profession as a nurse." (2)

This man also lost many friends who died from AIDS. When he combined his bereavement of being infected with HIV with the loss of his career, his thoughts about his life were explained as follows:

"I've been asked that if they find a cure for AIDS would I take it. And my answer is 'No'. It is not a process I wish to go through again. I've been through the grief of my having to die which was not easy and had to grieve of seeing

friends die. It is not a process I wish to go through again."
(2)

Furthermore, some people in this study sensed that they lost their opportunity to do many things. An inability to travel overseas because the fear of discrimination was an example. A man was unable to request personal insurance or a loan from a financial institution when his health status was "full blown AIDS".

"I can't get life insurance because I have AIDS. I can't buy a house because I've got no life insurance. I can't get a loan from the bank or anything, because as they said, why should we give you a loan when you can die in a year." (6)

For a woman, the decision not to have a baby or have a long-term relationship with her partner was made after knowing her HIV status. She felt loss of an opportunity to be a mother.

"The decision of not having children and relationships to a certain degree, like trying to find a long term relationship. I cannot have a baby."(10)

Suicidal attempts

Four people experienced suicide attempts on at least once to 13 occasions. Their suicidal thoughts and attempts did not develop before being diagnosed HIV positive or when they first had knowledge of their HIV status.

A man attempted suicide when his partner, who was not HIV infected, broke their relationship. Being HIV infected was considered the prime cause of the disrupted relationship.

"I convinced myself that the reason he left me was that if I had been HIV negative, everything would have been okay. So I went and drank far too much gin, sat in a hot bath tub and slashed my wrists." (9)

Experiencing multiple losses were associated with suicide of one man. He lost his partner who died from AIDS. After the death of his partner, the mother of his partner obtained legal ownership of the house in

which they had joint investment. His friends also rejected him when they knew that his partner died from AIDS. He felt that these situations were intolerable and endeavoured to attempt suicide.

"It was pointless going on, losing the house and losing everything, I've lost ... (his partner), I've lost everybody that I care about. I just grabbed a whole stack of pills and took them and all I did was sleep for 4 days." (3)

However, his thoughts of suicide were not persistent, but increased in intensity around festive times when happiness was supposedly shared with others. Times of celebrating became times of loneliness after the HIV infection was disclosed.

"I thought about it a couple of times since then, but I've never done anything else since. There was a stage a little while ago - Christmas time, New Year time - that was hard, that was really hard." (3)

For another man, suicide was attempted 13 times. He felt that his long-term illness with AIDS was agony and unbearable.

"Fed up. I'm sick and tired of every time I go to see the doctor. I get told something's wrong with me. I've lost weight. It's got to the stage I've had enough of shitting my pants, night sweats, 37 pills a day, weight loss, my friends dying, me, PCP pneumonia. I'm always sick. I tried to commit suicide 13 times. I've tried to kill myself because I can't handle it. I don't like having AIDS, but that doesn't seem to work. I'm still here. I tried to get myself run over by a truck six months ago and the truck missed me. So I'm still here." (6)

Furthermore, the man revealed that the precipitating events which led to his suicidal ideas were sometimes unable to be clarified.

"It just comes and goes, nothing needs to be said or nothing. It can be a dream." (6)

Dying from AIDS was also perceived too great a suffering and too painful to confront.

"I didn't want to die of AIDS as I had seen on the media people in the last stages of the disease. It caused me so much upset, so I thought it might be best if I did suicide. Then I wouldn't have to go through what others were suffering."(2)

In contrast, the two women in the study did not experience any suicidal ideas related to HIV infection. The first woman said that she had to be alive for her children. Another women pointed out that people who had HIV infection should fight the illness for longer living rather than make it shorter.

"A lot of people say if I was told I had AIDS, I'd kill myself. But it's funny, when you're told you've got a life-threatening illness and you've only got so long to live, you really want to live. You fight for living, rather than giving in." (10)

Dealing with the difficulties for surviving

People in this study developed multiple strategies to cope with various situations related to HIV infection for their survival. The strategies used included dealing with rejection by others, enhancing inner strength, organising a support network, maintaining optimum physical and mental health, sharing experiences with the public and planning for the future.

Dealing with the rejections. All people in the study experienced coping with the social rejections by either concealing their HIV status from others, isolating themselves from society, deciding to disclose their HIV status to others, or by ignoring the rejections experienced.

Being viewed as "lepers" or "gay plagues", some people decided not to tell anyone about being HIV positive. The secret was kept from their partners, families, friends, classmates, neighbours, and society in general following initial diagnosis of their HIV infection. The length of time of keeping the secret ranged from one week to ten years.

A man concealed his HIV status from everyone when he was first diagnosed with the HIV infection. He did not know how to deal with the diagnosis.

"I'm not going to tell anybody. I don't know what to say. I didn't know who to tell, or how to tell, or if I should tell. And I decided no, I was going to keep it to myself and not tell my brother or my partner or anybody. It wasn't easy." (3)

Another man concealed his HIV status for almost ten years. The secret was kept from his friends, relatives, and neighbours. He had never told the truth to anyone except his physician and the social workers. The researcher was the last to be included with those whom were told. He said he never experienced rejection from others.

"Why should I ring the bell and tell the people? I told them (his friends) I had cancer, because not many people I know. I am dying, so what should I tell them. I have very little friends, some people were dying and not because I'm ashamed, its only because I'm scared to lose the friends. The person who gave it to me maybe did not know he had it too." (7)

For some people, the decision not to disclose their HIV status to their significant others was made. Not wanting to worry or upset others was a reason given for their concealment. The people felt that disclosure would cause unnecessary or unhelpful emotional distress to those told, especially to any partner or family members. A man felt that his family would respond to his disclosure as being "too far away from reality." Therefore, he kept it a secret from his family for seven years until the illness worsened.

"I always knew that if I was telling people about it, they would feel sorry. They would feel pity. They would feel shattered. They would feel a lot of things that I wasn't feeling myself." (5)

HIV status was also concealed from colleagues. A woman worked as a child carer before being diagnosed with the HIV infection. She was unable

to disclose her HIV status to her employer and colleagues. She feared she might be dismissed.

"Working in child care would be the worst place to come out and say you've got HIV, because all the parents would be up in arms." (10)

Feelings of insecurity were another reason why another man concealed his HIV status. As he was not Australian born, he kept his illness a secret without seeking any support from others for almost two years. He felt fear of deportation.

"I was very reluctant because I didn't know where I was going to play all around. I was very suspicious about the AIDS counsellor. Were they going to tell police, tell to my job, tell to my government and everything because the ... council (AIDS support group) was a government institution? So, they might have a connection with the government." (1)

Being HIV infected was also viewed as being shameful. One man decided not to disclose his health status to others.

"They said, 'Oh poor boy.' I don't want to hear that." (9)

Disclosing HIV status to others was something the people in the study chose not to do, especially when it related to individual privacy. They felt the persons whom they told would be unable to provide helpful support and, therefore, there was no benefit in any disclosure. In addition, they would reject them rather than help them.

"My personal activities and personal health is none of my employee's business unless it affects my work." (8)

When asked what it was like to conceal her HIV positive diagnosis from others, a woman felt an alteration in her sense of sharing knowledge of her health status.

"It caused many people to not understand me. It was like having a double life, people were only knowing half about you." (10)

One man he felt morally ashamed of himself.

"I felt like a rationalisation, a justification for not being honest, for not being truthful." (9)

However, many people in the study were able to disclose their HIV status at a later date to those they trusted and to whom they would receive support. Those whom were told included their partners, close friends, and family members.

Several people were of the view that telling the truth about their HIV status to the partner was a morally honourable and responsible thing to do for lovers. They disclosed the HIV status with whom they decided to have a long-term relationship.

"It is part of my own personal ethos that if I want to be involved with these people, I have to tell them my status. It is unfair for them not to know." (9)

In addition, the disclosure about HIV infection to partners needed preparation. Maintaining intimacy and ensuring a level of trust in each relationship were considered important components of the disclosure to ensure that the partners accepted their HIV status. One man did not engage in any sexual relationship with his lover before his HIV status was disclosed.

"I wouldn't let him touch me for seven weeks, because I had to try and tell him what I had. So I took him to Mandurah for the weekend. We got a hotel and all that. I took him away and showed him that I can be a nice person. And then I just sat down on the beach and said, 'There's something I must tell you.' He said, 'What?' I said, 'I've got HIV and AIDS'." (6)

Another man refrained from telling his partner until he discovered that his partner and he were mutually compatible.

"We had four weeks of being together every day for long periods of time, talking about anything and everything under the sun. Going out for dinner, going to see the movies, learning about each other and then we both started

to feel like we could actually build something out of this. That was when I told him." (9)

In this case, the casual partners were excluded.

"Not all sexual partners. We had a few sessions and played. There was no disclosure." (8)

"I cannot infect them (his casual partners). They have to allow me to infect them. I cannot be responsible for their sexual health. They have to accept the risk of that. It was not necessary for them to know because we were both being very safe about what we were doing and how we were doing." (9)

For some people, the onset of physical symptoms, exacerbation of disease, and hospitalisation, had rendered disclosure of the infection as inevitable and unavoidable.

"I was sick. When I was very sick. I had to. I mean everybody knew that I was HIV because I didn't have any other choice. Everybody saw me at the hospital and I had to tell my family and to everybody because there was no other choice." (1)

In addition, a death from AIDS was not viewed the same as death from other illnesses. Disclosure of HIV status to members of the family before death was imminent, was considered necessary.

"If you die, they (participant's family) will be more upset because you didn't tell them. You see. So I have to tell to everybody." (1)

Even a housemate was told when moral concerns were implicated.

"Probably within 3 or 4 weeks, the first person I shared the information with was a guy I was sharing a house with because we were sharing a house in quite difficult circumstances." (8)

When asked what it was like when trying to disclose being HIV infected to others, a woman said she still felt fear of disrupting her relationships with others. The feelings persisted in her mind.

"Telling them that they've got to wear a condom is nothing, but telling them that you've got HIV is the pits. That feeling

hasn't changed at all. It's as a butterfly in your stomach. So you convince them ahead that they're not going to want to stay with you, but they stay. And for me it's hard for me to have sex with them straight away because your mind's still going through that negative attitude sort of thing. So you really need time to digest that they're going to stay. But you don't want them running out the door then because you think they might change their mind and not come back again. It's a nightmare, that hasn't changed over the nine years, it's still the same feeling. "(10)

Many study participants isolated themselves from others to deal with social rejections. They felt difficult to find someone who accepted "who they were."

"Because you get tired of ringing somebody up and say 'Do you want to go out for dinner, or how about we go and see a movie?' 'Oh no I'm busy.' And when you get that for a few weeks and then it comes into a couple of months and nobody rings you. And then I withdrew completely." (6)

The isolation was also practised to avoid development of close relationships or the building up of new relationships with others.

"I did find it easier on. I tended to isolate myself from others because I was afraid of being rejected and hurt. " (2)

Even though financial pressure developed, a man decided not to share his accommodation with others.

"I'd like to share my house with someone, but if I have someone to share my house with me, I've got to go and tell them what's wrong with me. I've got to go through the whole thing again." (6)

Furthermore, social isolation was utilised to "heal" oneself after being hurt by society. One man decided not to communicate with others. He spent additional times of solitude to identify what had happened to him, what he needed, and what he should do. The healing process took a long time.

"In the first three years, I needed to be alone because I was going through therapy, learning to like myself, learning to listen to the noises of my mind and not be afraid of them. Like in the darkness of the night, at two o'clock in the morning when you wake up and you are

alone with your own mind. I learned to live with that and I learned not to be afraid of that. So I needed that time alone, living with other people would have just kept me distracted. I wouldn't have been able to focus on that." (9)

Enhancing inner strength. A number of people in the study attempted to deal with the fear of death and inevitable social rejection by enhancing their inner strength. This strength was related to an acceptance of the illness, having a positive attitude, and the use of relaxation techniques.

Two of them perceived their behaviour before being diagnosed HIV infected as "self-destruction" as evidenced by their heavy alcohol drinking, smoking and practising unsafe sex. When their serological test results were found to be positive, they accepted the diagnosis.

"God, I think I've managed to do it. Because, remember, I was living a life of self-destruction. I was drinking too much. I was smoking too much. I was having unsafe sex everywhere."(9)

Another man philosophically accepted his diagnosis of HIV infection.

"I've accepted as my fate and karma and got on with life."
(8)

The acceptance of the diagnosis of HIV infection is also related to an individual's spirituality. One man believed that his soul would start upon a new journey to a new life and a new place after the body died. He expected that the result of his HIV testing would be positive.

"It was just confirmation, I didn't really bother. I'm glad to hear that".
(5)

When comparing AIDS with cancer, another man felt that living with HIV infection was easier.

"I don't feel as though I'm any worse off than anyone being diagnosed with cancer. You've just got to get on with life. I'm not worried for tomorrow, tomorrow may never come. So I live day by day." (7)

The acceptance of living with dying also contributed to the creation of a positive attitude towards HIV infection. Whenever one man confronted a difficult situation, he used a positive outlook to deal with each situation.

"I always look to the positive, even in a bad situation you can always create a positive. So I can't think of one (a negative situation) at the moment." (9)

Having HIV was also positively viewed by another man that it was an opportunity for reevaluating himself.

"The HIV virus gives me an opportunity to think about myself and using the time that I've got to think about things, differences and going to places to have a good time." (1)

Using the power of imagery, another regarded the HIV like a 'friend' within his body. When the HIV illness progressed such as a period of lethargy, it was like his "friend" was activating and greeting him as a companion.

"It was like a friend going to be there in my pocket and one day it is going to pop up." (5)

A woman perceived that having HIV infection caused a positive change to her family. She dedicated her life to her children:

"It brought me closer to the kids." (4)

In addition, two people used alternative forms of relaxation techniques to help them release any emotional distress and to understand themselves better. One practised meditation every day at home to relax and reevaluate his needs and life goals. A positive attitude towards self was perceived as the subsequent outcome.

"Yes, when you are relaxed and have empathy with yourself. You can fix everything. And before I didn't have much time to think about myself, because I was busy working and had a very good time going to parties and other things. Now you know...I think much more about

myself, about my life. I meditate and read and do things that before I couldn't do. (1)

In addition, generating hope for the present and future life had contributed to create the individuals' inner strength. A man believed he would be cured because he expected the invention of a cure for HIV infection.

"May be tomorrow they will find the tablets".(7)

Positive social attitudes toward HIV infected people were also expected.

"I've got a lot of hope that people will learn. I hope the message (AIDS education) gets through to people quicker, a lot sooner than what we expect." (6)

A woman reported that hope was generated when she achieved the goals she had set herself. She hoped to fight her sickness and continued making plans for her future life with the HIV.

"I'm achieving everything I want to do. Right now, to me I just don't think I can't. It's more. I'll try. They can only say no, but at least I'm going to ask." (10)

The feeling of hope also developed following recovery from a serious illness and suffering no adverse side effects from the prescribed medication. One man sensed that hope was generated when his T-cell count had increased dramatically from 500 to 1100 cells. Due to a similar outcome, another assumed that death was not imminent.

"I have been on AZT already nearly three and a half years. And I haven't had any reaction. I've been lucky." (1)

Seeking out support network. Each person in the study experienced the seeking out for support from individuals and groups. These supporters, as their carers, included their lovers, friends, families, volunteers, and staff members of AIDS community support groups. Carers' acceptance and the encouragement to deal with the HIV infection were considered as positive support.

In the beginning, seeking out for support was started from people who had a closer relationship with them. A man sought out support from his partner. Because his partner accepted his HIV status, he sensed that he had someone who cared for him and loved him.

"P.. (His partner) sat there, looked at me and said, 'We can work around this'. It was an immediate acceptance. It was, 'okay, I know the risks. I know everything and I am willing to be part of the situation'. His reaction was pure excellence". (9)

For another man, his friends were his significant others who supported him when he was under emotional and financial pressure.

"I've got wonderfully supportive friends. Letting me know that they are in a crisis situation or in possibly a financial situation. People (his friends) have been there." (8)

The others gained support from their families. These people sensed that they were cared for when their families were concerned about their illness, visited them, kept in contact with them if they were far away, and allowed them to stay with them in their home.

It was initially thought that support from the family might not be expected. A man prepared to say sorry to his family members when they first visited him in hospital and were told about the HIV infection. He expected his family would not accept him, but his presumption was wrong.

"Their reactions were very good, when they came to see me you know...immediately. My sister lives in ...(country) And my parents live in ...(country) with my brother. And they came to see me. They had very good reactions. My parents, I didn't expect that they would understand me. I thought they might get very upset. But they didn't you know. They didn't say anything." (1)

One woman in the study had support from only one person in her family, that was her mother. She sensed that having just one family member was fortunate for her.

"She's like trying to protect us. And as long as my Mum is there for us (the participant and her children) we don't need anybody else." (4)

The AIDS community support groups were the other networks contacted by many people. The unprejudiced and non-discriminated support, regardless of the fear of contagion, were perceived as the most important motivation for the people in the study to continue participation with the support groups.

A man was rejected by his lover, friends, and family. He only had support from the people in the community support groups.

"I've had a lot of support from loving and caring people in the community, they do not judge me but rather accept me for who I am and not what I am." (6)

For some people, more than one source of support was sought. A woman who had support from her mother felt comfortable when she brought her children with her to one support group at least twice a week over several years. She felt that meeting with the carers at the support center was as "a break in the day".

"The people here are really nice and it's good to be able to come here-everybody understands. They don't judge you or tell you to sit on the other side of the table. They treat you like you are normal people. And they help you if you need help. They will help you with things." (4)

A man who voluntarily participated with the carers in the support group sensed that there was no secrecy between the carers and him. The seriousness of the situation was turned to laughter on numerous occasions.

"I am actually very grateful to them. I can laugh with them. I can joke about my sickness. I don't have to keep a secret. There are people there for helping you." (7)

Experiencing being loved and cared for by many people at a support group, positively influenced another man's feeling of self-worth.

"Like I can go to the ... (AIDS support group) and they will cuddle me. They will ask me for help. I feel like I'm

wanted, I'm needed. It's good when somebody comes up and says, G..(participant's name) will you do this for me? I think, Wow! there are people out there who need me. There is life out there. I'm still wanted. I'm still loved and people still care for me. I've still got friends. As long as I've got friends, I've got life." (6)

Furthermore, having long-term support from the professional carer helped one man who felt diseased and experienced rejection from his partners to once again confront society and people within the community. The relationship with the carer as a member of the support group also moved toward an equal level. His counsellor came to be his friend.

"Now we meet on a more equal footing, it's not a client/counsellor relationship, now it's a friend type of thing and we discuss things on that level, not as counsellor/client."(9)

Not only did the people in the study sense that they gained psychological support, their physical needs were also met. The AIDS support group volunteers assisted a man to maintain an optimum level of activity when he stayed home with a physical disability after being discharged from the hospital.

"..... (Volunteers from the AIDS support group) came to see me all the time, almost 24 hours. So I mean in that sense I wasn't alone, because there were a lot of people. And they came and saw almost a day and then it became once a week and once a month. And now they come and see me every two or three months. And oh! I know I've got a lot of help." (1)

Some people in the study perceived that they had support from others who were also infected with HIV and were members of the community support groups.

"You don't get rejection from here because everybody is in the same boat. Everybody knows what you're going through because they're going through the same stuff, so you don't get the rejection and you don't get the fear." (3)

During a conversation with other members, a similar experience with those people was shared. They then provided support for each other.

"We'll sit down and have a cup of coffee and they'll ask me how long have I had it, so I tell them. Share what's happened to me with them and let them know that they're not the only ones out there. There are lots more of us and if you want a cuddle, we'll give you a cuddle. We've got information to share." (6)

Emotional distress was also alleviated when situations were seen in a humorous light. A man was released from the suffering of the adverse side effects of the medicine taken, when he spoke to another member of the group who had similar experience of drug side effects.

"I was able to sit down with another fellow. We were having a laugh about the fact that he fell out of the bath and knocked himself out. And I fell into the bath and hit my head on the tap and there's a big difference." (3)

However, two men reported that they had minimal participation with any HIV/AIDS community support groups. One man always sought out only the physical supports, such as transportation and massage. He preferred to deal with his problems by himself rather than have 'superficial chats' with others. Another man received support from his family and friends. He felt that seeking support from others was not seen as a requirement.

For some people who were not able to gain support from their own families, support from others who had experienced the loss of their significant others from AIDS was obtained.

"It is a very small group but it's very supportive. I've got a whole new group of friends - a very small group. But I can talk to them about anything, I don't get rejected." (3)

A woman's adopted mother was her former carer whose son had died from AIDS. She perceived that her carer understood her and knew how to care for her. She credited her carer with the carer's knowledge about

the patterns of the illness, the treatment process, and the emotional responses erupted as a result of the illness. In addition, she sensed that this type of support was not able to be provided by her own family.

"Just that I know that she knows what HIV is, she knows what it can do. She has an understanding of it, which my parents haven't bothered doing. It's like everyone when they get sick, like anyone. It doesn't matter if you're HIV or not, when you're sick, you want someone to fuss about you and hold your hand and say, 'poor baby you'll be all right.' And granted, my parents can't do it". (10)

Nonetheless, several people in the study perceived that the carers who had experienced the loss of their significant others from AIDS were 'available' for them when the support was needed.

"If you clicked your fingers, they'd be there." (10)

"I can talk to them all the time about how I feel and how I do." (6)

For one man, one of his carers and himself became supportive of each other.

"He (his carer) said he needed support and I supported him. He is the only person that I still have as a friend, that I've had for a long time. (3)

Since having support from the carers, the man became active in his social activities. His life was not as lonely as it was previously.

"And that is the first time that I've had anybody stay under the same roof as me since my partner died. Well I got breakfast in bed. He got up and made breakfast and I had breakfast in bed. And I'm going to have dinner with my buddy (another carer) and her husband tonight. Twelve months, two years ago there was none of that." (3)

He sensed that the support affected his feelings of hopefulness.

"I nearly died and I gave up. There was no reason for me to go on. I see any reason why I should even bother fighting, what's the point, I'm just going to get sick later on and die. But now I had support - I wasn't getting rejected this time and I fought. So I came good." (3)

Maintaining optimum physical and mental health. According to the perception that the curative treatment for the HIV infection might not be as expected, the people in the study used several ways to cope with being HIV infected.

A man denied that he was HIV infected, so as not to be a "worry machine."

"The denial part is that I just didn't want to accept. They (physicians) say to me, 'You're not well'. As far as I'm concerned, I feel well. I don't have a disease. I'm normal like everyone else." (6)

A woman avoided using public transportation to prevent opportunistic infections when she went out of her home.

"It's just the social thing, but I think it's more dangerous for me hopping on a bus and going to a shopping centre and doing my shopping. I mean because of all these infections and coughs and colds and bugs flying through the air and things like that." (4)

The 'extra' care of personal and environmental hygiene was also maintained when in company of her children or when dealing with her own health.

"They said that changing the nappies (her daughter's nappies) would be more dangerous to me than to her because of infections and different things. So I just had to make sure I was well up on the cleaning and sterilising. I mean now I clean and mop the floor two or three times a day, everything's got to be clean." (4)

Several people perceived the medical monitoring as being under pressure and life-threatening. The deterioration in the T-cell count or development of any illness were perceived as stressors. One man regularly followed up with his medical appointment. Although he experienced emotional distress when several kinds of illnesses developed, he still kept checking up on his health with his physician.

"I hate going to the hospital, I hate going to the doctor because when I leave I know I'm not going to leave with a cure. I'm going to be leaving with more bad news, but I've got to know what's happening to me." (6)

For some people who might not be able to tolerate the pressure, the follow up appointment with the physicians as usual were cancelled.

"They take you to hospital to cure something. And then while you're there, you catch something else. Then it becomes a cycle - to go into hospital to be cured of one thing to come out of hospital. Then you go back into hospital for something else." (9)

Even administering any medicine related to HIV infection was refused by several people in the study. The drugs were perceived to be extremely harmful and were believed to exacerbate the HIV infection. One man viewed that the side effects tended to lead to a "quicker death" rather than extend his life.

"I refused. I'm not interested. I see more people deteriorate on AZT than I've seen get better on it. I've lost probably 30 or 40 people over it in ten years." (8)

In addition, the quality of life was considered a reason to refuse treatment.

"I'm falling over all the time and I just feel lousy and I feel tired. So it's like a decision somebody's already said to me this morning, it's affecting the quality of my life. I'm going to stop it. I'm not going to take those particular tablets any more. I'm sick and tired of falling over." (3)

Other strategies were used to fight the HIV illness. One man explained how he tried to maintain optimal physical health:

"I do not drink. I don't smoke and go to bed early. Drinking is good if you do it a little bit. Late nights are not very good. I have a good sleep all the time. Eating properly and doing exercise is so important. You need something to help you when you have HIV you know." (1)

Natural substances such as herbs or plants were also used.

"I've tried lots and lots of natural therapies and medicines over the years. I know it doesn't hurt. It's just too expensive to go on trying." (4)

Stress was viewed as the factor influencing the physical deterioration caused by the HIV infection. The people avoided additional stress by using relaxation techniques such as meditation.

"The one thing I do try and do is to keep my stress level down. I'll do whatever it takes to get things back into perspective and keep a calm sort of thing." (10)

However, the maintenance of an optimum level of health was thought to be impossible if the illness became severe. One man struggled with his need for rehydration.

"I drink lots and lots of fluids because one of the HIV and AIDS problems is being very dehydrated. I went to the hospital last week and they said, L (participant's name), you're dehydrated again. My body doesn't have enough water in, and I'm trying to put it back, but I'm losing it. (6)

When medical treatments were not considered helpful, several people used alcohol and drugs to assist with the release of their emotional distress.

"The time that I became aware of my status (being HIV infected) I was running on some pretty heavy drugs at the time." (8)

However, the people finally discovered that these behaviours were harmful to their health.

"Using alcohol and soft drugs caused a lot of problems especially the alcohol. I was using them as a crutch in the hope that things would get better. But on the whole, it was unrealistic of me. I've learnt from that episode in my life by facing what was wrong with me." (2)

Sharing the experiences. Some people decided to disclose their HIV status and shared their experiences of living with the infection to members of the public.

One man spent time with the AIDS support groups educating others about his HIV illness and explaining to others how people reacted to him.

"Because I feel that I've had the virus for eleven and a half years. I know what it does. I know how hurt you can be. I know how nasty people can be. I know what it can do to you. There are so many people out there who don't know the truth, and they need to know. Someone has got to tell."(6)

One woman had experienced the caring for her son who was HIV positive. She decided to share her experiences of living with HIV infection with members of the public. She believed that education related to AIDS should be provided for children who might be HIV infected in the future.

"People have got to stop blaming each other and do something about it. Because if they don't do something about it, you never know, they're going to go home and find that they've got it, or their children have got it. Then what are they going to do?"(4)

Educating others was also related to the individual's self esteem. Another woman viewed that the sharing of her experience with members of the public was worthwhile because it decreased the risks of being HIV transmitted.

"I love it. Because when I do talks, if I can save one person, it's worth."(10)

Planning for the future. One woman thought and planned about her future following her HIV positive diagnosis.

"I'd been told I only had a year to live. I thought, OK, I'd like to go back working in ... (her workplace), because I wasn't working as a prostitute or anything like that any more. So I had to get money. I didn't want to go on the dole." (10)

Some people in the study, however, were determined to live in the present and tended to have a short-term future plan rather than a long-term plan.

"I see today as being real and consider the next 12 months as always being real. But as far as thinking in five years I'm going to achieve this, I've probably dropped that

pattern of thought. Perhaps because I think it's more unrealistic now."(8)

Many people had also made a decision about the ending of their lives. They talked about euthanasia as a way of ending their lives peacefully. Painless death and dying with dignity were the experiences desired when the time came.

"I don't want to lay in hospital and have someone wipe my bum for me. I want to be able to die with dignity. I want to be able to wipe my bottom, get up and go to the toilet, do my own washing in my house. The day I can't do that is the day I wish to choose euthanasia - I don't want someone to sit there and feel responsible to look after me." (10)

A man, even though he admired the family-like approach of the nursing staff in the hospital, wanted to die peacefully in his home. He wished to be in the company of his pets when he had reached the terminal stage of his life.

"If I become seriously ill and there is nothing they can do for me. I wish to be nursed and die at home. The reason is that the nursing staff cannot give their full attention to our dying patient. I would also like the company of my cats."(2)

Although euthanasia had been planned for the ending of their lives, it was considered to be flexible because the future remained uncertain.

"So you might make the plan, but it doesn't mean you'll follow through with it. At the moment I've got a plan. But when it gets to that point, I might think, 'I'll plan a bit later'. Because you don't know what your reaction will be until you get to the time."(10)

Summary of Themes Analysed

The experiences of the people with HIV infection in this study were contemplated in terms of how the HIV infection affected their lives. The people each experienced discrimination differently and from various sources. They experienced emotional disturbances which included overall

fear of dying, fear of dying alone, and fear of suffering. The feelings of confusion, anger, uncertainty, and loneliness were included in the experiences of emotional disturbances. Several physical and psychosocial changes were expressed in terms of physical changes, lifestyle changes, sexual behaviour changes, and attitudes towards self changes. There were perceived and/or actual losses over several aspects such as the loss of relationships, employment, and opportunity. Suicide was attempted by several participants for a variety of reasons. Many strategies were used to deal with such issues that affected their lives. Dealing with the rejection, enhancing inner strength, organising support networks, maintaining optimum health, sharing their experiences with members of the public, and planning for the future were some of the coping strategies revealed that ensured one's ability to survive.

CHAPTER FIVE

Discussion

This last chapter has been divided into two sections. Firstly, relevant literature that discusses the experiences of people living with HIV is highlighted in relation to each of the themes. Secondly, a second level of analysis in relation to nursing model is incorporated in order to promote additional discussion.

Discussion of Themes

The phenomenon of living with HIV emerged as a multifaceted experience, with numerous meanings. The different aspects of the experience of living with HIV infection are discussed under the six themes: social discrimination, emotional disturbances, changes, losses, suicide attempts, and dealing with difficulties for surviving.

Social discrimination

The findings from this study suggest that the people diagnosed with HIV infection experienced a great deal of discrimination which emerged as the phenomena of being stigmatised and rejected. The discrimination against these people altered their lives and relationships with others. The source of rejections were from family, lovers, friends, neighbours, colleagues, priests, health care workers, and people in the general community. These findings were similar to the studies of many authors in the USA (Bennett, 1990; Cohen, 1990; Crandall & Coleman, 1992; Laryea & Gein, 1993). The feelings of being "cut off" perceived by the study participants are also congruent with the report by Bennett (1990). That is people with HIV infection perceived various types of social rejections which included direct, obvious, subtle, and covert reactions.

The participants in this study viewed AIDS as "a social stigma" and perceived themselves as being stigmatised after their HIV status was

disclosed. Other authors also revealed similar findings (Crandall & Coleman, 1992; Eliason, 1993; Macks, 1988; Seigel & Krauss, 1991). This may have occurred because AIDS itself had symbolic representations (Hall, 1992). The symbolic metaphors about AIDS included a gay disease, evil, sinful, plague, or punishment, and an angry God.

Crandall and Coleman (1992) pointed out that social reactions toward people with HIV infection were related to two major factors: fear of contagion and other stigma toward homosexual people and intravenous drug users. It is evident that some study participants experienced being rejected by their families before the diagnosis of HIV infection was disclosed, particularly when the rejections were associated with their sexual identity and with the use of intravenous drugs. This "double whammy" appeared to be a complex set of factors which influenced the attitudes of people in general towards the study participants. It might have caused greater alteration of the relationships of the participants with their families.

Many people in the study experienced social rejections by being categorised as "lepers or plague infected", particularly in those people who were diagnosed with HIV for more than five years. Public media related to HIV prevention appeared to have an important role not only increasing public awareness of HIV, but also influenced individual attitudes towards the people with HIV infection. Although National AIDS campaigns seemed to influence the general public who had a greater fear of AIDS through causal transmission (Ross, Rigby, Rosser, Anagostou & Brown, 1990), Altman (1992) reported that the media images presented to the Australian public tended to promote fear and hatred of AIDS rather than compassion and understanding.

Both genders experienced negative social reactions towards them. However, some differences were found. For the male participants, their experiences of being rejected were most likely associated with other people

in the homosexual community whereas the women's experiences appeared to be related to their families. This may have occurred because of their different lifestyles.

Seigel and Krauss (1991) reported that people with HIV experienced negative reactions from others in the homosexual community. This study supports the result that people with HIV were viewed as having "poor practice" and "low standards". This phenomenon may be discussed in terms of self protection amongst homosexual people. Since the AIDS epidemic began, homosexual relationships have been an important vector of HIV transmission and homosexual persons have been viewed as a group of people who are at risk (Crandall, 1991; Douglas et al., 1985; Eliason, 1993; Scherer et al., 1991). However, being viewed as a group of HIV carriers has caused many people in the homosexual communities to fight against these negative attitudes (Lowy & Ross, 1994). Therefore, the rejections of the homosexual community towards the study participants may be explained as avoiding relationships with high risk people who are infected with HIV. It is also evident that people who are well dressed and have high standards of living may appear to be a lower risk amongst people in the homosexual community (Lowy & Ross, 1994).

Emotional Disturbances

The findings from this study reveal that HIV infection has an extreme effect on individual emotional balance. The study participants were of the view that people living with HIV infection were in and out of a 'cycle' of emotional distress while they were alive from the time they had been diagnosed with HIV. This distress included confusion, fear related to death and dying, uncertainty, anger, and loneliness. Similar emotional disturbances have also been reported by many researchers (Coward, 1994; Chuang et al., 1989; Nichols, 1985; Remein et al., 1992; Salisbury, 1986).

The emotional disturbances mostly expressed by the study participants were the feelings of fear related to death and dying. They had the view that the HIV diagnosis was a "death sentence" given by the physicians. The meaning of living with the fear of dying perceived by those with HIV was like being "worry machines" that initially started after their diagnosis of HIV. These findings are congruent with the study by McClain and Gramling (1992). The authors indicated that the feelings of fear related to death and dying were perceived as the major stressors amongst the people with HIV infection. Remein et al., (1992) also reported that the hardest part of being diagnosed with HIV infection was the ability to confront mortality.

The fear of dying may be explained as a common human response to terminal illness which is not different from that of other fatal diseases, such as cancer, and scleroderma (Viney, et al., 1989). However, the findings revealed several factors which might activate the feelings of fear differently from those of others. These included being unprepared for the HIV test, a lack of support because of social rejection, physical deterioration from the HIV illness, and the experience of death of significant others from AIDS. In this study, these factors combined to influence the feelings of fear in each participant. Similar findings were also reported by other researchers (Chuang et al, 1989; Cohen, 1990; Firn, 1995; Grant, Padilla, Ferrell & Rhiner, 1990; Martin & Dean, 1993).

Surprisingly, two participants reported that they had no experience of the fear of dying. The predominant characteristics of the two participants was the age of the first and the strong spiritual beliefs of the second. Reed (1987) found that older participants with HIV infection expressed less psychological distress than younger ones. Congruently, the majority of the study participants with HIV infection were young or middle aged adults (18-45 years) and did express a fear of dying. In addition, the people with

HIV who managed a lifestyle based on spiritual beliefs, were not afraid to die (Ragsdale, Kotarba & Marrow, 1994).

The study participants also experienced confusion after they were diagnosed with HIV infection. It was found that the question "Why me?" was often asked by people with potentially fatal diseases (O'Connor, Wicker & Gemino, 1990). The findings suggest that experiences of confusion were related to the diagnosis of HIV infection and physical illnesses related to HIV. They did not know what happened next. Being diagnosed HIV positive was reported as a crisis situation in which support was needed (McClain & Gramling, 1992). The feelings of confusion may be explained as the human response to the changes in an individual's physical health when the course of an illness is unknown (Cohen, 1990). In addition, Lowy and Ross (1994) found in their study that some Australian homosexual people believed that HIV infection would never happen to them because they practised safe sex. In fact, the researchers found that the practise of safe sex as described by those people, still rendered them at high risk of HIV transmission due to incorrect practices.

The experiences of anger by several participants in this study were also reported in several previous studies (Bennett, 1990; Holland & Tross, 1985; Viney, Henry, Walker & Crooks 1991). Holland and Tross (1985) found that the feelings of anger experienced by the people with HIV infection were expressed both directly and indirectly. In this study, both types of anger were also found. For example, many participants felt direct anger toward the people who infected them, toward the HIV that affected their life span, and toward the people who rejected them. Indirectly, one participant reported that he felt angry about everyone when first diagnosed with the HIV infection.

For some participants, feelings of anger were interrelated with feelings of guilt when they thought that they placed themselves at risk of

the HIV. This finding is congruent with the recent study by Miller and Riccio (1990). These authors found that people with HIV felt guilty when they thought that they might spread the HIV to others.

Several researchers reported that people with HIV infection experienced feelings of uncertainty (Holland & Tross, 1985; Maj, 1990; Laryea & Gein, 1993; Viney et al., 1991). This study supports these results. The participants described the feelings of uncertainty related to the future course of the illness, social reactions and their future. These feelings of uncertainty may be explained as normal human responses to the uncertainty of one's life which may not be different from other people with other fatal illnesses (Viney et al., 1991).

Shultz (1988) purported that a deficiency of social interaction, or missing something in one's life, can cause an individual to feel loneliness. Congruently, the study participants, particularly symptomatic participants who were homosexual, reported that they felt loneliness. This is partly because people who are homosexual may feel lonely if they are frequently ostracised by their families and by society in general (Kehoe, 1990). People with HIV participating in this study felt lonely when they experienced prejudice and discrimination, when they experienced loss of their significant others (who either died from AIDS or disapproved of the HIV status), or when they perceived that they had to confront multiple losses and changes when on their own. Some of these findings agreed with Berger and Mallon (1993) where feelings of loneliness were more likely to be reported by people with HIV infection who lived alone. In addition, the demand for support from those with HIV increases when physical illness develops, whereas support may not be provided to those with HIV as a result of social rejections (Turner et al., 1993). However, not all participants reported feelings of loneliness, including the oldest participant and the two women in the study. These may have occurred because the women

appeared to have larger support networks than the men, and older people usually have less social activities than the young (Turner et al., 1993).

Changes

Physical changes. It is unavoidable that HIV infection causes physical impairment. Previous research has reported that people with symptomatic HIV experienced fatigue, sleep disturbance, multiple infections, and disabilities (Darko, McCutchan, Kripke, Gillin & Christian, 1992; Tindall et al., 1994). Findings from this study support this previous research. Not only did the study participants have to struggle with physical changes, but their lifestyles, sexual behaviour, and attitudes towards themselves were also altered.

Lifestyle changes. The findings showed that lifestyles of the people with the HIV infection in this study were altered and directly related to the HIV infection. According to Ragsdale et al. (1994), life changes amongst people with HIV infection was based on medical and situational reasons. In this study, medical reasons may be exemplified as the HIV illness itself. Fatigue has been commonly reported as a major physical change affecting participants' activities of daily living and the lack of employment. More attention was given to their physical and environmental hygiene. Situational reasons appeared to be the impact of HIV, including social rejection and financial pressure. These led the participants to limit their social activities and isolate themselves from others by spending most of their time at home.

Sexual behaviour changes. Sexual behaviour changes amongst people with HIV infection have been reported by several researchers (Bennett & Koop, 1987; Bennett, 1991; Seigel & Raveis, 1993). The people living with HIV infection in this study also reported sexual behaviour changes as well as changes in attitudes towards a sexual relationship.

Sexual behaviour is considered an important part of an individual's life (Bennett, 1991) and can affect an individual's quality of life (Tindall et al., 1994). According to Tindall et al., human sexuality of people with HIV can be affected by a deteriorated health status as in other chronic illnesses. In this study, the participants viewed sexual relationships as the "worst enemy" that they had to deal with. Many people had adopted celibacy. Reasons for this change in their sexual behaviour included feeling unclean in themselves, fear of transmission of the HIV to others, desire for more out of a relationship than sex, conflicting sexual identity, and a lack of knowledge about sexual negotiation. These reasons were also found in homosexual people whether their HIV test was positive or negative (Seigel & Reveis, 1993). However, the findings from this study indicated that the fear of transmitting the HIV to others was the major reason for the study participants to adopt celibacy. This was confirmed by their expressions of having mentally active sexual sensations. Celibate practices were reported by the study participants of both genders. Nonetheless, this study focussed on deeper understanding as to what it was like being celibate. Experiences of loss of intimacy, loss of companionship and loneliness were expressed by the study participants. For one participant, these changes occurred due to the adoption of celibacy and led to the feeling of being less of a human being.

Attitude towards self changes. Attitudes toward self-changes of people living with HIV in this study were more likely related to an individual's self image and self-esteem. Self-changes have been reported in other studies. HIV affects an individual's self image when physical appearance deteriorates (Bennett, 1991) and physical functions are impaired (Laryea & Gein, 1993). Being infected with a transmitted fatal disease also caused people infected with HIV to feel shameful and diseased (Seigel & Krauss, 1991). In addition, the impact of HIV, which included being

unwanted by others, loss of relationships, and changes in individual lifestyles, may affect an individual's self esteem (O'Brien & Pfeifer, 1993). Some participants in this study reported low self-esteem before being diagnosed with HIV infection. This appeared to be associated with unemployment, having a homosexual relationship, and using intravenous drugs. In these cases, experiencing HIV infection and being rejected by others may have been the contributing factors that increased the feelings of lowered self-esteem.

Interestingly, two participants reported that their self-esteem increased after they were diagnosed with HIV infection. This may have occurred when these people accepted the diagnosis of HIV and utilised a positive outlook as a coping strategy. Having HIV was then viewed as an opportunity to gain social support (Lang, 1991; Turner et al., 1993), to reevaluate their needs, and to regain their inner strength (Coward, 1994). From this point, there was an improvement in the individual's self-worth.

Losses

Losses experienced by people who participated in this study were more likely related to an absence of interpersonal relationships, unemployment, and loss of opportunities. The losses of relationships were explained in terms of being rejected by others, and losing their significant others who had died from AIDS. The loss of their career was more likely related to the deterioration of their health and inability to face social rejection. This finding is also similar to the study by McCurdy, Schenker, and Samuels (1991) where work loss was at a much higher rate in people with symptomatic HIV than in those with asymptomatic infection. In addition, the authors reported that the nature of work in the job held during the first onset of symptoms, also affected their subsequent work status. For example, one participant was unable to continue in a position due to possible transmission of the infection. The loss of opportunity was

expressed in terms of financial loans, parenthood, and long term future plans. Similar findings have been reported by several researchers (Kermode, 1995; Laryea & Gein, 1993; Martin & Dean, 1993).

In this study, the experiences of loss amongst people with HIV infection was profound. The aspects of social rejection in conjunction with the terminal illness exacerbated the experience. The effects of loss related to HIV infection on an individual may be clarified by one participant's expression that medical treatment would be refused, even if a curative treatment for the virus were to be invented.

Suicide attempts

The experiences of suicidal thoughts and attempts amongst people with HIV infections were reported by many authors (Mazurk et al., 1988; McKegney & O'Dowd, 1992; Orr et al., 1990; Perry et al., 1990). In this study, it is evident that the participants living with HIV infection were at an elevated risk for suicide. They experienced both suicidal thoughts and attempts. The suicidal thoughts reported, appeared to be associated with psychological distress which included loss of one's lover related to AIDS, the fear of suffering death, and chronic illness. Recent research has shown that suicidal thoughts possibly occur either before or after an HIV diagnosis (Rabkin, Remein, Katoff & Williams, 1993). The authors purported that the majority of suicide attempts occur during adolescence and are very often associated with family rejection, anticipated hostility, or religious problems. Other patients with chronic illness, such as cancer, may also have an increased suicide rate (Whitlock, 1986). What is particularly interesting in this study is that no participant who attempted suicide, experienced suicidal thoughts before the diagnosis of HIV. Not only can the illness itself affect the individual with thoughts of suicide, but it is able to induce psychological distress related to the loss of significant others and social rejection related to HIV/AIDS. Biological changes also cause suicidal

thoughts if chronic depression due to a long term illness develops (Marzuk et al, 1988). This may explain the numerous attempt of suicide by one participant who were a long-term survivor with full blown AIDS.

Two participants who were intravenous drug users reported no experience of suicide attempts. A small sample size may not be sufficient to explain this phenomenon. However, Van Haastrecht, Mientjes, Van Den Hock, and Continho (1994) found that positive HIV status did not appear to lead to a sudden and substantial rise in suicide death of intravenous drug users. Therefore, further research is needed to investigate this phenomenon.

Dealing with the difficulties for surviving

People with HIV infection participating in this study had to deal with many difficulties for surviving. Many coping strategies were employed which included concealing their HIV status, disclosing their HIV status to someone, and isolating themselves from others. Other strategies included enhancing an inner strength, maintaining optimum health, sharing the experiences of living with HIV infection with members of the public, and planning for the future. The use of these strategies has been reported in a number of studies (Hays et al., 1993; Laryea & Gein, 1993; McClain & Gramling, 1992; Seigel & Krauss, 1991).

Dealing with the social rejections. Previous research has reported that people with HIV concealed their HIV status from others to avoid emotional distress created by being rejected by others (Hays et al., 1993; Pallack, 1993), disrupting relationships with others (Laryea & Gein, 1993), and to protect the family (Seigel & Krauss, 1991). Findings from this study support these results. The study participants kept their HIV status a secret from others because they feared being rejected and they wished to prevent their significant others from emotional distress. In addition, the sense of privacy and the feelings of insecurity were also found as contributing factors for concealing the HIV status of the study participants. Evidently,

the fear of being rejected appeared to be a major reason given for their need of self-protection.

The experiences of keeping the HIV status a secret from others dramatically affected an individual's sense of sharing and moral self. One participant perceived the experience as having a double life that was not able to be shared with others. Another felt dishonest at not being able to tell another about the fatal sexually transmitted disease. It was such a stressful experience for those people with the HIV to maintain the secrecy, when in actual fact support was needed.

Mandel (1986) suggested that disclosure of the HIV status to trusted individuals who would be able to help people with HIV infection deal with emotional distress, is necessary. The findings in this study also revealed that the study participants required someone with whom they could share their experiences, such as a lover, partner, or close friend. This finding supports earlier research in that significant others are the people with whom persons infected with HIV feel most comfortable and satisfied (Vaux & Harrison, 1985).

Seigel and Krauss (1991) reported that physical deterioration of HIV related illness may induce people to disclose their HIV status. Congruently, some participants in this study chose to tell their families about their HIV status when their illness became worse, particularly when they were hospitalised, and therefore, no longer able to to hide the illness.

Interestingly, moral concerns were raised in determining as to whom they should reveal their HIV status. In this study, the participants determined that disclosing their HIV status to their partner was an honourable thing that a person should do for a lover. The participants anticipated a positive outcome by preparing their partners both emotionally and physically for this disclosure.

Unlike their lovers, the study participants avoided telling their sexual partners about their HIV status. Seigel and Krauss (1991) suggested that anticipation of rejection by those who were told and the belief that they practised safe sex were possible factors influencing the concealment of HIV status to a casual partner.

In addition to the selective concealment and disclosure of HIV status to others, social isolation was another strategy used to deal with the feelings of social rejection. Social isolation as experienced by people with HIV participating in this study occurred in two different ways: being isolated from others, and isolating themselves from others. Shultz (1988) described social isolation as a situation where a person desires social contact with others, but is unable to make that contact. In this study, the participants were isolated from others due to being socially rejected. This was most likely related to their physical impairment. However, the people also chose to isolate themselves from others to avoid confronting their hurtful negative reactions. The social withdrawal amongst people with HIV infection was also reported by Seigel and Krauss (1991).

Enhancing inner strength. People living with HIV infection in this study had enhanced their inner strength to cope with many situations in their lives. The strength was associated with an acceptance of the diagnosis, having a positive outlook, using relaxation techniques, and generating hope. These findings are supported by previous research. Coward (1994) found that the well being of people with HIV was related to an acceptance of living with the infection. Katoff (1992) reported that having a positive outlook or the willingness to live as important factors that influenced longer survival.

This study supports the study by Remein et al. (1992) that spiritual and philosophical beliefs were used as a strategy to enhance individual strength. One participant, who believed in life after death, used this

philosophical belief as a coping strategy. Other participants who were able to accept the diagnosis of HIV infection used meditation to reevaluate their needs and decrease the fear of dying.

In addition, recent research has shown that religious beliefs were used to cope with emotional distress (McClain & Gramling, 1992; Ragsdale, Kotarba & Marrow, 1992). However, religious beliefs of participants in this study were less likely to be used to enhance inner strength or to cope with difficulties. This may have occurred for a number of reasons. Firstly, some participants experienced discrimination from some religious people. Secondly, being homosexual was considered by many with Christian beliefs to be sinful (Hall, 1992). The majority of participants were homosexual and were all raised in Christian families. This may have influenced them to anticipate the lack of approval of their sexual identity by other Christians. Thirdly, the participants were not a homogenous group and the majority were self-proclaimed homosexuals. Therefore, information related to the utilisation of religious beliefs to create an individual inner strength may not be easily seen due to the small sample size. A study of a larger group may be necessary for further investigation.

The feelings of hopelessness amongst people with HIV infection have been reported by several researchers (Cohen, 1990; Remein et al., 1992). Interestingly, such feelings were not reported by the participants in this study. Meanings of hope from the perspective of the study participants were captured in terms of achieving a set short-term goal set, hope for positive public attitudes towards them, and hope for having a longer life. This may have occurred because the majority of participants had support at least from the community support groups.

Seeking support network. Findings suggest that significant others, community AIDS support groups, other people who had HIV infection, and carers who experienced loss of their significant others from AIDS, were the

support network of people with HIV in this study. More than one source was employed by each participant.

Dobratz (1993) claimed that social support should be considered in relation to four dimensions; intimacy, social interaction, worth, and assistance. Based on these four dimensions, the participant who was rejected by former partners felt personally diseased. A lack of intimacy was expressed. In contrast, the present partner accepted the HIV status and provided support. Experiences of having hope were reported to the researcher. These findings may lead to a conclusion that a sense of intimacy is able to be maintained if support from a partner or lover is perceived.

Having support from family members was also important. The findings suggested that the participants needed family support, but it might not be forthcoming. For some participants, family support was not available due to there being no living relatives or to being rejected by the family. However, the findings from this study may not be useful to explain family support to a great extent as the sample size was too small. Further investigation may be necessary to explore how many people receive support from their families and how the support affects the value and meanings of their lives.

The findings revealed that participants who were asymptomatic were more likely to employ less support from community groups. These findings are congruent with the study by Pakenham, Dadds, and Terry (1994) who found that social supports were correlated with health status. The worse the illness, the more support was needed. For the participants who accessed support groups, the findings clearly revealed how emotional distress was alleviated. The support provided appeared to enhance the quality of their lives. The participants had an opportunity to maintain social activities with people who accepted them. Not only emotional support was provided to the participants, but physical support and counselling were

also included. These findings agree with other studies where social support positively affected an individual's psychological status (Hays et al., 1992; Pakenham et al., 1994).

Another interesting aspect from the findings was the support from people who experienced the death of their significant others from AIDS. It appeared that the carers provided credible supports for the study participants, particularly for those who were not able to seek out support from their families and lovers. The carers seemed to provide them with the support from all areas of the four dimensions. Feelings of loneliness and lowered self-esteem seemed to be positively affected by this type of support. Social interactions and a sense of being loved and cared for were gained. The participants admired the availability of the carers who supported them. These findings may imply that the availability of the carers is an important factor in providing support for the people with HIV infection.

Maintaining optimum health. The findings showed that people with HIV were highly aware of their health and had tried to maintain optimum physical and mental health. These findings were in agreement with previous research that people with HIV infection paid more attention to their personal hygiene, tried to eat proper food, exercised and had regular medical monitoring (Hall, 1992; McClain & Gramling, 1992; Remein et al., 1992). In addition, the study participants also believed that stress could affect their health status, thus their emotional distress needed to be controlled.

Although the participants had monitored their health regularly, several people, particularly asymptomatic participants, had refused medical treatment related to the HIV. These findings corroborated the study of Seigel and Krauss (1991). This may have occurred because these participants had previous experiences of suffering from the adverse side

effects of medication. As the participants were usually aware of their health, they may have sensed that the side effects could shorten their lives. In addition, one participant expressed the view that the medication affected his activities of daily living which resulted in a lowered quality of life. The final reason could be that curative effects of HIV medication has not yet been seen.

Denial was also used to release the "cycle" of emotional distress. To maintain a sense of 'normalcy' some participants avoided confronting the reality of being HIV infected. The use of toxic drugs (narcotic drugs) or alcohol was also reported when their emotional distress was intolerable, although they knew that these substances were harmful to their health.

Sharing the experiences. Several participants experienced sharing their experiences of having HIV with members of the public. It appeared to be that the sharing was done when the participants accepted the diagnosis of HIV and perceived that they were able to cope with any social reactions that might have happened. Ragsdale et al. (1992) found that some people with HIV would have liked to share their experiences with members of the public because they needed social interaction. The sharing may also help them to gain an individual sense of "honour" and "dignity". The experiences of sharing by the study participants appeared to be associated with the individuals' self-worth and maintenance of actualisation through helping others.

Planning for the future. Future plans of the participants in this study were identified. There was planning for achievement and planning for the end of life. The short-term plan was related to career achievements. For example, one participant went back to college and searched for career choices after being diagnosed with HIV. Short-term career goals were included in the plan. These findings are in agreement with Seigel and Krauss (1991) that people with HIV infection perceived career choices and

achievement as a key component in their sense of normalcy. These authors also found that people with HIV tried to achieve set goals after being diagnosed with HIV. This may have occurred because people with life threatening diseases recognised their mortality (Fryback, 1993; O'Conner et al., 1990). They may have needed to deal with a sense of urgency about the time remaining.

The people with HIV in this study were concerned about the process of dying. They anticipated a painless death, an ability to maintain activities of daily living, being with significant others before they died, and to die with dignity. Planning for euthanasia was perceived as help to cope with these anticipations.

Relationship of The Study Findings to Nursing Theory

Although none of the nursing models or theories was designed as a framework for this study, it was anticipated that the findings would correspond to some degree with a nursing model or theory. According to the findings, the experiences of people with HIV infection in this study portrayed how HIV infection affected individuals living with the infection. It appeared that Roy's Adaptation Model was relevant to this study to a certain extent. This model was then used to provide a second level of analysis for the findings.

Human as an adaptive system

In the adaptation model (Roy, 1984) an individual is viewed as a holistic adaptive system that receives input from the self and the environment, and responds to the output. The human system has a capacity to adjust to change in the environment as well as to affect the environment. The inputs for the person have been termed stimuli. The environment stimuli may appear externally or internally. The output is a function of input stimuli or the person's adaptation level through a major coping mechanism in the form of an adaptive response.

Inputs

According to Roy and Andrews (1991), the inputs are internal or external changes or stimuli which affect the behaviour of the person. Three classifications of stimuli which affect an adaptation of the person are focal, contextual, and residual stimuli.

The focal stimuli are the stimuli which most immediately confront the person (Calvillo & Flaskerud, 1993). In this study, the focal stimulus immediately confronting the participants appeared to be the HIV infection. Several participants were threatened by the diagnosis of HIV infection, which for them was perceived as a possible source of premature death. They experienced fear of dying when they were first diagnosed with the HIV infection.

The contextual stimuli include all other stimuli or environmental factors present in the situation (Lutjens, 1991). These stimuli are not the center of the person's attention, but contribute to the effect caused by the focal stimuli. The people in this study were affected by social rejection, stigmatisation, and social discrimination. Social support was an additional factor. These environmental influences may denote contextual stimuli that contribute to the behaviour caused by the HIV infection. Since the people were diagnosed with HIV infection, they were concerned about their relationships with others and their security. However, the intensity of socially negative attitudes and reactions towards people with HIV, appeared to become focal stimuli after they were diagnosed with HIV infection.

The residual stimuli are environmental factors that affect the person. The effects of these stimuli in the current situation are unclear (Roy & Andrews, 1991). The influences of age, gender, culture, length of illness, and spiritual belief may be determined as residual stimuli (Roy, 1984). The author further suggested that after the residual stimuli were validated, they

became either focal or contextual stimuli. In this study, the oldest participant and the participant who had his own spiritual belief did not fear death. Another participant was concerned about who would care for the three children following death. Therefore, the age, spiritual belief and gender of the participants may be viewed as residual stimuli that need to be verified in a larger group.

Coping mechanisms

According to Roy (1984), the three types of stimuli of focal, contextual and residual stimuli, make up the adaptation level or the ability of the person to cope with environmental changes. Coping mechanisms, which are the use of behaviour in response to stimuli, are categorised into two types: regulator and cognator (Lutjens, 1991). The regulator is used primarily to cope with physiological stimuli. The cognator is mainly used to cope with psychosocial stimuli. Responses which can be adaptive or ineffective provide feedback to the human system and become a new input to the person (Frank & Lang, 1990). The responses to the new input allow a person to decide whether to increase or decrease his/her coping strategies. However, Roy (1984) explained that the process of coping mechanisms were unable to be observed. Therefore, only the observable responses to living with HIV infection of the study participants are discussed.

Adaptive modes

Roy (1984) identified four adaptive modes which interrelated with each other. These included the physiological mode, self-concept mode, role function mode, and interdependence mode. Calvillo and Flaskerud (1993) purported that each adaptive mode in Roy's Adaptation Model represented a group of behaviours that promoted the individual's movement towards the general goals. These goals included basic needs of the individual (such as survival, growth, reproduction, and mastery of human system).

Physical mode. The physical mode involved the body's basic needs regarding physical changes (Blue et al., 1994). At the time of the interview, some participants reported HIV symptoms that developed according to the nature of the infection. These included lethargy, *Pneumocystis carinii* pneumonia, chronic diarrhoea, meningitis, ulceration in the oral, anal and genital organs, and a decrease in the number of T-cells. In response to the physical changes, some participants tried to maintain their optimal health by utilising several strategies. These included eating, exercising and sleeping adequately, caring for their personal and environmental hygiene, as well as attending for medical monitoring. However, some participants refused to be treated with medication related to AIDS in order to avoid the adverse side effects of the medication. This was perceived as a life-threatening factor. Limited social activities when lethargy developed were also included in the responses.

Self-concept mode. This mode is a basic need for psychic integrity which is composed of beliefs and feelings about oneself at a given time (Blue et al, 1994). The self concept mode is formed when a person perceives others' reactions and directs these to oneself (Lutjens, 1991).

According to Roy (1984) this self-concept mode is divided into two subareas; a physical self and a personal self. Physical self is described as the person's appraisal of attributes, appearance, functioning, sensation, sexuality, and wellness-illness status. The personal self is defined as the appraisal of one's own characteristics, expectations, values, and worth.

The physical self is further divided into body sensation and body image (Roy & Andrews, 1991). An individual's body sensation is described as how one feels about oneself (Lutjens, 1991). Having HIV infection remarkably affected the body sensation of people in this study. For example, some participants felt "unclean" and "diseased" when they realised that they were infected with HIV, or when they received various

degrees of inconsiderate treatment and care from health care workers. Body image is described as how one thinks one's body looks and how one feels about how one's body looks. In this study, one participant expressed feeling different from other people when being rejected by friends. Body image was a focus of another participant who felt less attractive to others.

According to Roy and Andrews (1991) personal self has been further divided into self-consistency, self-ideal or self expectancy, and the moral-ethical-spiritual self. Self-consistency is described as the individual's actual performance, the individual's response to a situation. Self-expectancy is a personal self component related to what one expects to be or to do. Moral-ethical-spiritual self is an individual's belief system, moral, and the evaluator of who one is.

The function of self-consistency is to maintain a consistent self-organisation to avoid disequilibrium (Roy & Andrews, 1991). In this study, the participants' self consistency was disturbed. Emotional imbalance was reported by all participants. Several of them perceived that the diagnosis of HIV was a 'death sentence' given to them. The knowledge that a curative treatment for HIV had not been invented influenced the participants to develop overall fears of dying, fear of suffering, and fear of dying alone. They also experienced uncertainty of their illness and their future lives. Living with HIV was perceived as being "in and out" of an emotional cycle and an "active vibrant human being" who became a "worry machine".

Self-expectancy of the study participants was affected when it related to the HIV infection and social rejections. The experiences of lifestyle changes reflected the limitation of their abilities to do things that they would like to do. For example, many study participants reported an inability to maintain their careers and recreation activities. They had difficulty getting financial support. These experiences portrayed how the

study participants were unable to fulfill their needs or to achieve their life goal as they would have liked.

Changes in self-value and worth were also reported by the study participants. Several sensed that the HIV infection lowered their self-esteem through social rejection and disruption of relationships with significant others. The impact of the HIV infection on the individuals' moral-self was explained by the experiences of guilt and alteration in their spiritual beliefs. Several participants felt guilty when they realised that they had put themselves at risk to the HIV infection and they might have transmitted the HIV to others. An alteration in an individual's religious beliefs was reported when rejection by others was experienced in religious places such as in the church. The change in spiritual belief was expressed by one participant who felt unable to cope with being infected with the HIV.

"My spiritual life is lacking, because I do become disheartened and have feelings of not being worthy of God's love and mercy. Also I don't have enough trust that God will help me when I am in need."(2)

In response to the alterations in the self-concept, the participants enhanced their inner strength by acceptance of the diagnosis of HIV infection. Having a positive outlook was used to identify various situations, particularly when they experienced socially negative reactions from others. Having HIV infection was viewed as a positive opportunity for them to reevaluate themselves and to become involved in the support network. Meditation was also utilised to release the emotional distress. In addition, some chose to share their experiences related to HIV infection with members of the public. The sharing was perceived as a "worthwhile" social activity for them in helping the community to learn about HIV illness. Other responses to the changes included the use of drugs and alcohol, denial of the reality that they were infected with HIV, and suicide attempts.

Role function mode. The role function mode is a basic need for social integrity (Lutjens, 1991). Roy (1984) believed that all people had their own roles in society and people needed to know who they were in relation to others. In this study, being infected with HIV had affected the people's functions in all or some of their roles in three major aspects. These included the roles of a sexual human being, a family member, and social roles (such as career and social actions).

It is known that a sexual relationship is one vector for HIV transmission. The participants' sexual relationship with their lovers or partners was altered because of the fear of contagion. The perception of a sexual relationship became "the worst enemy" that they had to deal with. Breaking up the relationship with a partner and practising celibacy were utilised by the study participants to cope with the alteration in their sexual roles.

Changes in familial roles were experienced. For example, one participant became a single parent when the partner left because of the fear of contagion. Two participants experienced being rejected by their parents and were unable to gain support from them.

For the social roles, many study participants experienced loss of career which was related to their deteriorating physical health, limited finances, and social rejection. The deteriorating physical health affected the participants when they became physically incapable of working. Their social activities were also altered as a result of their limited finance. Some participants responded to the fear of rejection in the work place by concealing the HIV status from colleagues and/or choosing to resign from their career.

Interdependence mode. The interdependence mode focusses on a social interaction related to giving and receiving love, respect, and human values (Roy & Andrews, 1991). This mode is based on the belief that

affectional adequacy or the feeling of security in nurturing relationships is a human basic need (Calvillo & Flaskerud, 1993). This need can be fulfilled through social interactions. Significant others and support systems are two specific relationships in this mode (Griffiths-Jones & Walker, 1993) .

The feeling of loneliness is a common ineffective adaptation resulting from a disruption to the interdependence mode (Roy & Andrews, 1991). The limited social interactions of the participants in this study were in relation to negative social reactions and their physical deterioration. Several participants experienced being rejected by their lovers, partners, families, friends, neighbours, health care workers, and society in general. The rejections led to a lack of social support for these people. In addition, the decreasing motivation to go out was induced by lethargy and physical disabilities. The participants then spent most of their time at home and experienced feelings of loneliness.

The response to the alteration in the interdependence mode included either concealing the HIV status from others or disclosing the HIV status to others. Other responses included either isolating themselves from others or disclosing the HIV status to others in order to seek support.

Responses

According to Roy (1984) human behaviour is defined as a response under specified circumstances. The output of behaviour shows how well people adapt to environmental change in two major categories: adaptive and ineffective responses. Adaptive responses promote positive outcomes which contribute to the goals of adaptation. Ineffective responses, on the other hand, are behaviours that do not promote positive outcome and tend to worsen the goals of adaptation.

Referring to the four adaptive modes, the people with HIV in this study utilised many strategies in response to the complexity of HIV infection, social stigmatisation, and terminal illness. It appeared to be that

the participants effectively responded to living with HIV infection. They were able to enhance their inner strength by having a positive outlook, accepting the diagnosis of HIV infection, generating hope, maintaining their optimum health, sharing their experiences with members of the public, and seeking out support from others.

In addition, Roy (1984) suggested that in judging effectiveness of the adaptation, the effect of the behaviour on the general goals of adaptation (which were survival, growth, reproduction, or mastery) was determined and the person's individual goals were a major consideration. Roy postulated that sheer survival might not be the person's highest goal at a certain stage of illness. In this study, euthanasia was planned by many study participants in order to promote their dignity and a pain-free death. This response was then categorised as an adaptive response.

Ineffective responses were identified which included concealing the HIV status from others, denial, attempting suicide, and the use of drugs and alcohol. These behaviours subsequently appeared became negative contextual stimuli for them. For example, the participants experienced fear of disclosure when they concealed their HIV status. Feelings of loneliness were experienced when the participants isolated themselves from others.

In the broadest sense, Roy's Adaptation Model seems as if it can be applied to explain the lived experiences of people living with HIV in this study. However, aspects of effectiveness of human response need to be discussed. Many people with HIV infection in this study responded to the fear of dying by refusing medical treatment related to AIDS. As the cure and effective symptomatic treatment for HIV infection have not been found, the study participants had monitored their own physical health regularly. They seemed to be aware of any illness that occurred to them. The deteriorated health related to the adverse side effects of the medication taken was experienced and perceived as a life-threatening illness that

altered their quality of life. In this case, the refusal to the treatment related to AIDS may be viewed as an adaptive response for the participants. However, the refusal of treatment also affect the progression of HIV illness which may be viewed as ineffective response. In another instance, the study

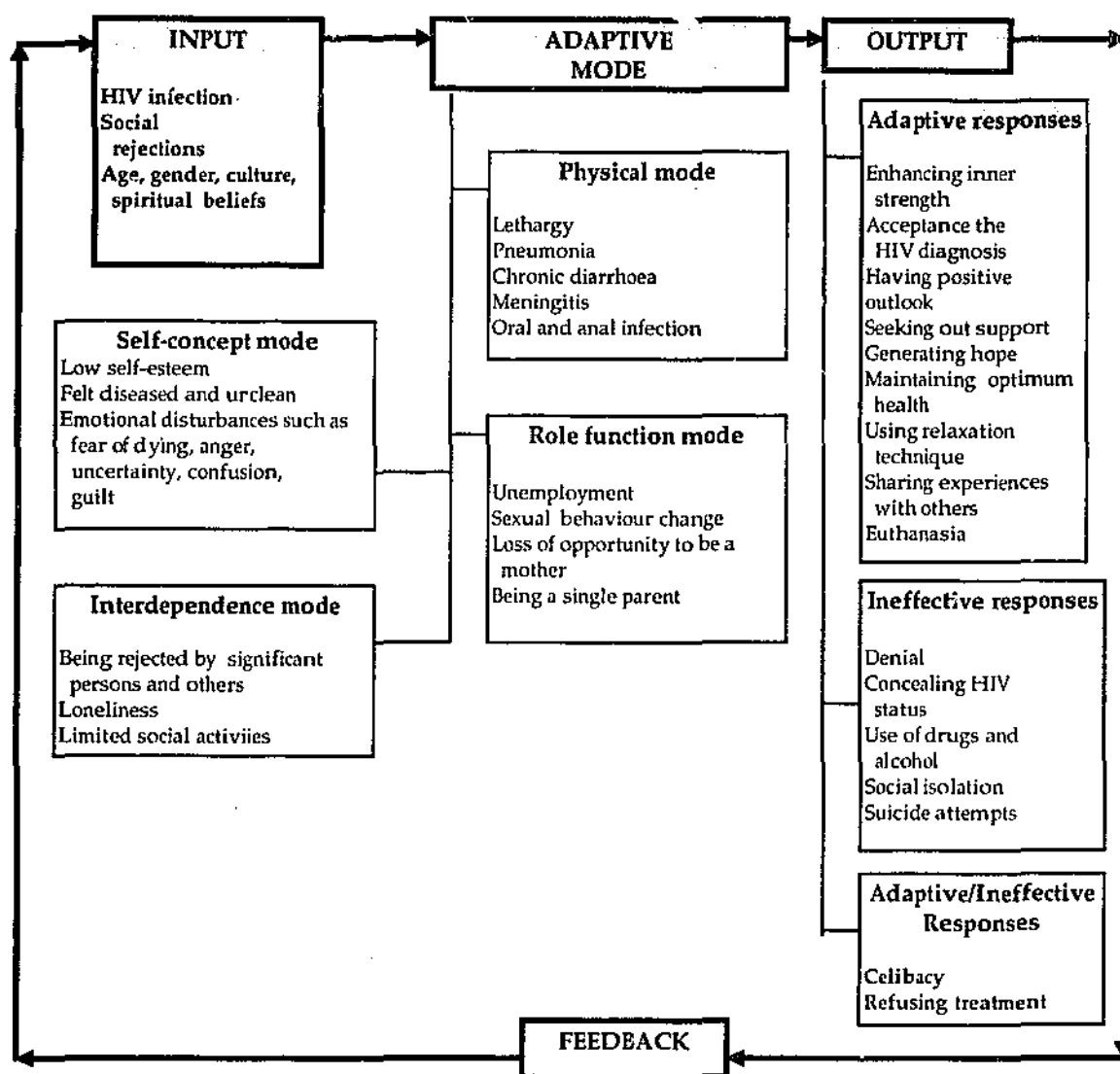


Figure 1. The correspondence of the lived experienced of people living with HIV to Roy's Adaptation Model

participants chose to adopt celibacy when they experienced feelings of being unclean, guilt feelings, and the lack of courage to negotiate with their

partners. Such distress might be released when they adopted celibacy. However, loss of intimacy was also reported. Therefore, it remained unclear whether the refusal of the AIDS related treatment was an adaptive or inadaptive response to the fear of dying as well as their need to practise celibacy.

In conclusion, the findings from this study appear to correspond to Roy's Adaptation Model to a certain extent (see Figure 1). The experiences of people living with HIV infection in this study portrayed a profound impact on the individual's physical and psychosocial aspects of life. Overall, areas of physical, personal, and social adaptive modes were involved. The findings revealed both adaptive and inadaptive behaviours of the people with HIV infection in the study. However, this model was unable to explain the refusal of the AIDS treatment and the practising celibacy by some study participants in terms of whether the response was adaptive or ineffective.

CHAPTER SIX

Conclusion

This chapter has been divided into four sections. A conclusive summary is detailed. This is followed by the implications of the study relevant to nursing and the limitations of this study. Lastly recommendations for further research are provided.

Summary of study

The purpose of this phenomenological study was to investigate the lived experiences of people living with HIV infection. The findings indicated that having HIV infection affected all aspects of an individual's life. The meaning of living with HIV infection for the participants in this study was captured into six major themes which included social discrimination, emotional disturbances, changes, losses, suicide attempts, and dealing with the difficulties.

The participants experienced social discrimination, social rejection, and stigmatisation from various sources. These included lovers, families, friends, colleagues, religious groups, health care workers, and society in general. It was also found that the discrimination against these people was in conjunction with other social stigmas such as homophobia and the rejection of intravenous drug users.

A great amount of emotional disturbance was reported in relation to the HIV illness itself and its impact which included social rejection, loss, and disruption of relationships with others. They experienced feelings of fear related to death and dying, anger, confusion, uncertainty, guilt, and loneliness.

The study participants experienced multiple changes and losses. They endured tremendous hardship of their physical changes, lifestyle changes, sexual behaviour changes as well as attitudes towards self

changes. They experienced loss of relationships with their significant others because of the fear of contagion. Their experiences of financial pressures were related to their unemployment. An inability to access financial support and insurance from other sources was perceived as loss of their opportunity to fulfil their financial requirements.

All participants realised that their sexual relationships would put others at risk of HIV transmission, particularly their partners. It was difficult for them to maintain their sexual relationships when the sexual desire was active. The fear of rejection and transmission of the HIV to others influenced many study participants to adopt celibate practices. As a consequence of practising celibacy, many study participants experienced a lack of exchanging intimacy with their lovers and became lonely.

Several people with HIV infection in this study experienced suicide attempts. The factors precipitating suicide attempts were related to the loss of significant others who had died from AIDS, disruption of relationships with a lover, and fear of suffering death from AIDS. Psychological distress developed in relation to long-term illness and subsequently influenced suicide attempts.

The study participants had tried to deal with the difficulties by utilising various strategies. Concealing HIV status and isolating themselves from others was used to avoid facing social rejection. Alternatively, disclosing the HIV status to those they trusted was used to obtain emotional support. Emotional distress related to the fear of dying was released by maintaining optimum health. Medical monitoring was regularly practised. However, some participants refused the AIDS-related treatment due to the side effects caused by the medications prescribed. Drugs and alcohol were also used when the distress was uncontrollable.

Several participants had enhanced their inner strength to struggle with the tremendous difficulties. They accepted the diagnosis of HIV

infection. Positive outlook was created as well as using relaxation techniques to release the strain and reevaluate their needs. In addition, some participants had support, both emotional and physical, from their significant others and support groups. The support received appeared to increase their self-esteem. The people coped with the uncertainty to their illness and their lives by planning short-term goals. Euthanasia had also been planned to promote a painless death and dying with dignity.

The experiences of living with HIV/AIDS captured in this study lead to the conclusion that HIV infection had a significant effect on an individual's day-to-day living. The dimensions underlying this phenomenon, the experiences of living with HIV were identified and presented as the effects of chronic illness, terminal illness, and social stigmatisation on human beings. This study indicated that people with HIV infection needed intense support from various sources, including significant others of the people with HIV, health care workers, and society in general.

Furthermore, the application of Roy's Adaptation Model enabled the researcher to explain and discuss the full range of human responses to living with HIV infection in this study. The findings revealed that the study participants reacted to their living with HIV infection by both adaptive and ineffective responses. The knowledge established is of benefit for future testing of Roy's adaptation Model in explaining the phenomenon of living with HIV infection.

Implications

The implications of this study may be discussed in accordance with the ultimate aim of the inquiry. The willingness of people with HIV to participate in this research was to share their experiences with larger groups of people with HIV infection, families, society, and other professions. Therefore, the greater understanding about living with HIV

infection can lead to greater advocacy for the study participants and others experiencing HIV infection.

As a phenomenological study can generate a direction for nursing knowledge and practices, this study demonstrated a need for a multifaceted educational approach related to caring for people in general with HIV illness. Not only health care workers but the public still lack information about AIDS transmission. Their negative attitudes towards people with HIV infection remarkably influenced the psychosocial well being of these people. For nursing education, the cognitive based knowledge in caring for people with HIV illness alone may not be sufficient to provide for the varying needs of student nurses. AIDS related curriculum must be designed to provide specific concerns on all aspects that affect the well being of these people. This includes HIV knowledge, attitudes towards people with HIV and towards people with other AIDS related stigmas, and practices. Counselling techniques need to be addressed in the curriculum. This knowledge will enrich with holistic and humanistic perspectives, and can then be applied in practice to enhance the care required for people with HIV.

Psychological support is needed from the beginning of when HIV testing is considered until the patient's life has ended. Active listening with positive attitudes towards these people will help nurses to support people experiencing the emotional distress accompanying HIV infection. To engage fully in interventions, people with HIV must perceive being valued and trusted by the nurse's unconditional positive regard for human life. These approaches will help them to create client/nurse relationships that will subsequently lead to quality of care for their patients.

The diagnosis of HIV infection was perceived as 'a death sentence'. Nurses need to ensure that support is obtainable when the test is requested. Nurses are one of the support sources that can help the people to regain

composure following the crisis of being diagnosed with HIV infection by providing prompt and effective counselling. The relationship between the patients and their family needs to be evaluated in order to organise appropriate family support. Counselling for the family may need to be provided.

In the case of symptomatic HIV infection, nurses need to evaluate the patients' ability to maintain their optimum physical health as well as their emotional distress related to the fear of dying. The patient's self-care may need to be guided, such as personal hygiene, proper activities of daily living, and simple relaxation techniques. In addition, there is a need for an awareness that adverse side effects to the medication taken may lead to accidents.

It is also necessary to address the notion that people with AIDS require extra support and care when they are terminal and near death. The support needed should be at least obtained from both their significant others and health care workers. Painless death and death with dignity should be promoted for their clients.

The people with HIV and their carers experienced grief and loss related to the death of their significant others who died from AIDS. Emotional support for a family and significant others following the death of people with AIDS is necessary.

This study also has implications for nursing administration. Nurse administrators may need to access support both for people with HIV infection and nurses who are the care givers. As a product of the close and continuous relationships between nurses and their patients, a consensus between the nurses and the nurse administrator is necessary in order to reach a level of quality of care for their clients. For example, the nurse administrators should be able to contact with other agencies who are able to provide support for the patients such as community support groups. In

addition, nurses are at risk in caring for patients with HIV infection. Occupational health issues should be regularly monitored and supported by the administrators; for example, emotional distress of nurses in caring for patients with HIV.

Not only has this study implications for the nursing profession, but other health care workers and the public in general are also concerned. Many participants in this study experienced unemployment, even though they were not terminal. The reasons for being unemployed were more likely related to the fear of rejection, emotional distress, and the uncertainty of their capabilities to work. In this case, occupational therapy and/or reskilling is necessary to help these people maintain their social roles and increase their self-worth.

In addition, the nursing profession itself may not be able to provide support for the people with HIV infection effectively if other sources of support are not incorporated. This study indicated that a support network had an important role in helping people with HIV cope with the social rejection, and where family support was not available. The cooperation amongst these health care agencies as a network needs to be strengthened. It will result in greater benefits not only for the people experiencing HIV infection but also for the caregivers themselves.

Limitations

The limitations of this study are similar to the limitations of all phenomenological studies. Van Manen (1990) purported that there was a lack of proof that the findings of a phenomenological study were reliable, generalisable, and objectively valid. Although the creditability of the study was identified, generalisation is cautioned because of the small number of participants who were able to provide a purposeful sample selection. The findings, therefore, may be of no aid to prediction (Plager, 1994).

In addition, the majority of the participants were obtained from the community support groups which may have influenced their thoughts, activities, and attitudes. Therefore, the findings may not be representative of others diagnosed with HIV infection in general.

Recommendations

People experiencing HIV infection in this study may not represent the larger group of people living with HIV infection. Therefore, it is essential that further existential validation for the phenomenological perspective and the human understanding facilitated by the method, be researched. With greater understanding, phenomena surrounding living with HIV infection may be understood through research and caring connections rather than through continued silence.

This study aimed to investigate individual experiences of people living with HIV infection. However, the analysis of data does not permit the researcher to arrive at a definite conclusion owing to the heterogeneity of the participants. These included gender, age groups, risk behaviours, and stage of illness. It is recommended that study of a homogeneous group may enable other researchers to unfold the reality of people experiencing HIV infection and uncover these limitations. Recommendations for future research are:

1. Social support and coping strategies came to light during the analysis. Further research will require other researchers to make a more concerted effort to include participants who are less connected with the community support groups. It is also necessary to explore how people with HIV receive support from their families and how the support affects the value and meanings of their lives. Research in relation to the use of religious beliefs to enhance an individual's inner strength is also required.
2. As this study had only two female participants, a basic knowledge about the experiences of women infected with HIV should be developed

and lead to future research in several aspects. These included the experiences of female intravenous drug users who are infected with HIV, mothers who are infected with HIV, and the suicidal thoughts among women infected with HIV.

3. The second level of analysis of the experiences of living with HIV in this study corresponded to Roy's Adaptation Model to a certain degree. However, the Model may need further validation with scientific enquiry. Further research to test the use of the Model with people with HIV illness is recommended. The validated Model can then be widely utilised in all areas of nursing which includes research, practice, administration, and education.

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Appendix A
Information and Consent Form

Information Form

Dear Sir/Madam

I am currently conducting a study as a final part of a Master Degree in Nursing at Edith Cowan University. The purpose of this study is to investigate your experience of living with HIV/AIDS. I am hoping that the results of this study will assist in understanding persons having HIV infection. Not only do I hope for a change in social attitude, but the results may contribute to our knowledge in caring for persons with HIV/AIDS.

I would like your permission to include you in this study. Your information will be very valuable and important to help people uncover and understand the real experience of HIV infected persons. The study will take approximately an hour of your time for interview. This will involve asking you to describe your experience after having HIV infection.

Your participation is purely voluntary, and you may withdraw at anytime. Whether you agree to participate or refuse to do so, your treatment will not be affected in anyway. You will remain anonymous in the study results.

If you agree to participate, please sign the initial of your first name on the consent form at the bottom part of this letter. Thank you for your time.

Nongluck Suwisith

Consent Form

I.....
Initial Name

have read and understood the information and agree to participate in this study. I have had the method of maintaining my anonymity explained to me. I am assured that my identity will not be disclosed during the study or when the study is completed. All my questions have been answered to my satisfaction.

Signed-Informant.....Date.....

Signed-Researcher.....Date.....

Appendix B

Prompt questions

1. What is your experience of having HIV infection?
2. Can you tell me how you feel about having HIV infection?
3. How does the infection affect your day-to-day living?
4. Can you describe the impact of this effect on your day-to-day living?

Appendix C

Code Transcript Sample

Content/verbatim quotes	Codes/Tentative Themes
<p>Case No. 4 And for some reason I thought it had probably got a good hold on me now. My t-cell count wasn't very good - it was really low and I sort of thought this is it. My brother's dying, my partner's dying and he was infected at the same time. My brother's partner had just died a month before and I thought, well, this is it, I'm going to die very shortly.</p> <p>There were a few changes. I don't work any more. My health goes up and down. If there's a cold around I catch it. A twenty four hour wog, I get it. I get tired. I don't have a lot of energy. I get depressed a lot. When you're not feeling 100%, it tends to get you down. My personal life has changed because I don't have my partner any more and that's a big change and that's HIV. I mean that's taken my partner and I'm on my own and after 40 years. That's a long time to be on your own. I don't want to get involved in making new friends because either you're going to die or they're going to die - that's in the back of your mind all the time. I suppose that's probably the thing.</p> <p>Case No. 6 I tried to commit suicide 13 times. I've tried to kill myself because I can't handle it. I don't like having AIDS, but that doesn't seem to work. I'm still here. I tried to get myself run over by a truck six months ago and the truck missed me. So I'm still here. I'm not meant to die yet. Because I felt like no-one understood me. No-one knows what I'm going through.</p> <p>Case No. 9 I felt diseased. I felt nobody would possibly want to have a relationship with me. When I told the first one, thinking that this person and I could work together well and he screamed and ran away, it was a case of well, that would seem to be about the standard reaction. I don't think anybody else is going to react too differently to that. It was really very soul-shattering to have that reaction happen.</p>	<p>Fear of dying increased The illness was getting worse, the fear of dying increased. Someone who had a close relationship with the participant died from AIDS.</p> <p>EMOTIONAL DISTURBANCE</p> <p>Inability to work related to physical impairment LIFESTYLE CHANGE Prone to be infected with common infections. Fatigue PHYSICAL CHANGE Physical deterioration influenced psychological distress EMOTIONAL DISTURBANCE Loss of intimate relationship LOSS</p> <p>Had no desire to build up a new relationship with others. It related to the perception about death and dying. Social isolation DEALING WITH THE DIFFICULTIES</p> <p>Suicide attempts Felt unable to live with AIDS</p> <p>Felt lonely EMOTIONAL DISTURBANCE</p> <p>Attitudes towards self changes felt being rejected CHANGE</p> <p>Perceived that everyone would rejected him. Being rejected from others was hurtful. SOCIAL REJECTION/STIGMATISATION</p>