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**OCCUPATIONAL ADAPTATION - THE LIVED  
EXPERIENCE OF FATHERS WITH HIV/AIDS**

**A dissertation submitted in partial fulfillment of the  
requirements for the degree of Master of Science in  
Occupational Therapy**

**University of Cape Town  
Division of Occupational Therapy  
Department of Health and Rehabilitation Sciences**

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DECLARATION

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**Tribute to the Participants**

***“It feels to me as if...it feels to me,  
I feel important and I feel well and I can still do things.  
Yes, I can still be a father.”***

**“J” July 2001**

## DEFINITION OF TERMS

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**Human occupation** – this term refers to *“chunks of activity that are personally meaningful and are named by the lexicon of the culture that humans engage in”* (Clark et al, 1991, p. 303)

**Occupational motivation** - occupations are engaged in because they meet species-specific, survival or other higher level needs' (Wilcock, 1998).

**Occupations of fathering** – refers to all the things fathers do when they are *“doing fathering”* (Townsend, 1999, p. 58).

**Health** – The World Health Organization defines health as being a *“a state of complete physical, mental and social well-being, not merely the absence of disease or infirmity”* (WHO, 1946).

**Health context** - this context is created by *“...and lived by people in the setting of their everyday life.... Health is created by caring for oneself and others, by being able to make decisions and have control over one's life circumstances, and by ensuring that the society that one lives in creates conditions that allow the attainment of health by all its members”* (Ottawa Charter, 1986, p.iii-v).

**Vital needs** – this refers to basic needs that *“are rooted in the physiological organization of man, and result in eating, drinking and sleeping. The satisfaction of vital needs serve to expose man to the extending needs of his widening environment”* (Du Toit, 1964, p.4).

**Relatedness** - within phenomenology, this concept refers to  
“... our relatedness to our fellowman that has the power either to make the “world” – i.e. everything inherent or in contact with man, such as his body, time and things either acceptable, and so “near”, as to be within him, or, on the other hand unacceptable, in all its negative degrees, and so remote, as to be entirely “without” or “outside” him” (Du Toit, 1964, p. 5).

**Meaning** – Du Toit (1964) emphasized that man’s primary meaning in life lies in the quality of his relatedness to God or the transcendental. She stressed that the “quality of man’s relationship with his God, and that with his fellowman, are interdependent” (ibid, p5) and is “extended or limited by the other” (ibid, p. 5). This definition gives meaning a central position within occupation. It reflects the quality of the relatedness between an individual and his adaptation context.

**Reflection** – Du Toit (1964) distinguishes between a condition of pre-reflection or general awareness and reflection or thinking that identifies and categorizes.

**Adaptation** – this term refers to “an active response to a challenge in the environment that is self-reinforcing and that becomes most effective when it is organized subcortically as an unreflected habit” (Frank, 1996, p. 47). It is the ability to engage with the environment in a personally-meaningful and culturally-meaningful manner.

**Occupational Adaptation** – can be regarded as a normative occupational process used throughout a person’s lifespan in order to achieve mastery of occupational challenges (Schultz & Schade, 1992) and to fulfill the purpose of one’s life (Du Toit, 1964). Adaptation is achieved “through doing” (Frank, 1996).

**Occupational therapy** - refers to a rehabilitation modality that by means of participation in meaningful (Frank, 1996) and purposeful occupation, aims to restore to a client “*. .an ability to participate in Life, and enabling him to assume that degree of personal responsibility which his residual physical and mental capacity permits*” (Du Toit, 1964, p.7).

**Human ecosystem** – this refers to the range of activities and resources that are available at any one time (Frank, 1996). This includes the quality of the interrelationships between individuals and these factors and the manner in which they are organized.

**Proxy occupations** (Reseacher, 2002) - Frank (1996) intimated that it was necessary to act on behalf of the client while the client was unable to assume full responsibility. This may be a temporary, intermittent or permanent requirement. Proxy occupations refer to the things occupational therapists need to do to enable and empower the client to engage in the next adaptive level.

**Creative Ability** - Du Toit (1970, p. 23), used this term to characterize the individual “*by his ability to form a relational contact with people, events and materials, and by his preparedness to function freely and with originality at his maximum level of competence.*” Creative ability was manifested in a tangible or intangible product and reflected the level of psychical development of the individual.

## ABSTRACT

This qualitative, phenomenological study describes fathers' living with HIV/AIDS' experience of **occupational adaptation**. Rich data was gathered through unstructured interviews. The data was analyzed by thematic analysis. The levels describing the fathers' living with HIV/AIDS' experience of occupational adaptation, emerged as **adaptive occupations** and **proxy occupations**. The themes included **The crisis of living: *you got nothing really in your hand***; **Disengaging from the known: *toe kon ek nie wegkyk nie- then I could not look away***; **Engaging with the unknown: *who will take care?*** **Reconfiguring fathering: *I can still be a father***; **Beyond fathering: *making a way***. The fathers' self identity became transformed from a father living in poverty, to a father living with HIV/AIDS, to a person who is an occupational being. These core adaptive occupations were made within their personal-family context. In order to experience self-realization, the fathers required the occupational therapist and 'others' to apply proxy occupations to prepare the next adaptive context namely, the community and work contexts, for their occupational adaptation. Implications of the findings are discussed with reference to father's living with HIV/AIDS, policy makers, occupational scientists and occupational therapists.

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This work is a product of its time and the special contributions of a number of persons:

### **To A, J, G**

*"...by following a pattern in and out of time before and beyond the here and now, one discovers one's own specific sense of meaning..."* (Van Der Post, 1991, p. 32). Thank you for allowing me to be part of this journey.

### **To Professor Ruth Watson**

For understanding the complexities and asymmetries of the human spirit and for believing in me - thank you.

### **To my daughter Julie**

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**CHAPTER 1: INTRODUCTION**

University of Cape Town

## CHAPTER 1: INTRODUCTION

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This qualitative research study utilizes knowledge about HIV/AIDS, health and illness, human occupation and occupational adaptation. Frank (1991) considered the illness experience to be a natural part of life that altered the human being, but still placed the need to be regarded equal to other human beings as the primary need. He expressed this succinctly when he said:

*“ To understand what **the rights of the ill** mean, we must ask what is required to produce one’s self as a human being. This kind of production first requires care from others, and then it requires time, space, basic comforts, and some level of aesthetic choice. Ultimately it requires that the conditions of our lives enable us to return to others something of the care we have received. All this is necessary if we are to experience life rather than just survive it. None of these rights should be anything special.”* Frank (1991, p. 120).

This study will explore and describe the chronic illness experience of fathers living with HIV/AIDS and their perception of what they need to produce themselves as human beings – through the process of occupational adaptation.

### **1.1 Developing the rationale for the study**

The rationale for the study was developed by examining attitudes towards illness and attitudes towards people with the HIV/AIDS illness to establish whether their conditions of living are equal to persons living without illnesses.

In addition, the literature review showed that there was an absence in current occupational therapy literature – that deals with HIV/AIDS in the South African context and that deals with fathers, their phenomenological experience of the HIV/AIDS illness and its impact on their fathering occupations, in the national and international contexts.

### **1.1.1 Normalizing Illness**

The World Health Organization (WHO) redefined health as being inclusive of illness (WHO, 1986) thus, providing the impetus for considering that individuals and populations with illnesses shared the same rights as those without illnesses, to equal and healthy living. WHO (2001) began considering other aspects of societal living (other than medical conditions) such as negative attitudes and lack of resources which prevented equal and healthy living and were responsible for illness or that augmented illnesses. The aim was to identify which conditions of living (or contexts) contributed to or exacerbated health disorders. This view was in opposition to the traditional view (Frank, 1991) that persons with illnesses are less valuable to society because they are unable to participate in occupation and are economically unproductive.

In response to this negative view of persons with illnesses or limitations, whether temporary or permanent, the Disability Movements throughout the world tasked themselves with bringing the needs of persons with disabilities to the forefront of society in order to reassert their right to equal and healthy living.

In the same manner, it is expected of health professionals and health consumers in rehabilitation, to assert the rights of persons with acute and chronic illnesses (and those persons at risk for these illnesses) to appropriate rehabilitation services to promote their adaptation towards equal and healthy living. Pizzi (1990, p. 45) advocated for a change in thinking that demanded *“that people with HIV/AIDS are viewed as vital, functional, productive and contributing members of society “*.

### **1.1.2 The HIV/AIDS epidemic in South Africa**

HIV/AIDS, in contrast with other epidemics is regarded as an international pandemic because it continues to grow exponentially in countries throughout the world. 71% of the global human immuno-deficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) is found in sub-Saharan Africa (Mhalu, 2000). The developing countries, such as South Africa, are considered to be the most affected and 95% of all new infections (due to heterosexual intercourse) are reported to occur there (ibid, 2000). The same author reported that 70% of the new infections occurred in sub-Saharan Africa. In Africa and sub-Saharan Africa, the HIV retrovirus is reported to thrive because populations of persons tend to be highly mobile, more than half of them live in poverty, there is a high level of ignorance, women in comparison with men have a low socioeconomic status, there is an existing high prevalence of infections such as tuberculosis and sexually transmitted diseases which facilitate HIV transmission or increase the viral load, persons engage in unprotected sex and believe in cultural taboos (Kriener, 1999 and Mhalu, 2000).

Furthermore, Mcoup (2000) reported that the full range of virus types i.e. HIV-1 and HIV-2, with their subtypes, M, N, O are all present in African countries. Thus the likelihood of becoming infected is higher in the African countries. In addition, Karim & Karim (2000) reported that in sub-Saharan Africa more women compared to men were infected with HIV. This trend was being observed throughout the world.

In South Africa, approximately 22,8% of the population are infected with HIV while approximately 1,700 new infections occur daily (Department of Health, 1999). The Medical Research Council (M. R. C., 2001) reported that 40% of adult deaths in the age range of 15 – 49 years in the year 2000 were due to HIV/AIDS. Predictions are that the life expectancy of adults will change from 65 years to 40 years by 2010 (ibid, 2001). Hence, while the prevalence rate is high and the incidence rate is growing daily, the mortality rate is predicted to accelerate by approximately one generation of working-age adults within one decade. Thus the predictions are that many young persons will die from HIV/AIDS. This trend can reverse the developmental gains made in developing the skills of working persons and can contribute to increasing poverty as a result of lack of income-generation and increasing medical-related costs.

Another direct consequence is that large numbers of children will be orphaned because their parents will die from HIV/AIDS. According to the Department of Health (1998), by 2010 there will be two million orphans living with grandparents, extended families, foster homes or in institutions in South Africa. Shell (2001) argued that a large number of children will also die as a result of HIV/AIDS due to vertical or mother-to-child transmission and that this trend would control the numbers of living orphans.

Because of the large mobile and migratory workforce in South Africa, men are particularly vulnerable to being infected by and to infecting women with the HIV retrovirus. The unequal power relations amongst African men and women, the cultural symbol of a large number of children as representing a high self-worth, general ignorance and existing cultural taboos make men susceptible to reciprocal transmission of HIV. This value system also makes women and children particularly vulnerable to HIV infection.

HIV/AIDS is now recognized as a slow disease, with a duration of 7 – 10 years for adults after diagnosis (Ostrow et al, 1999). When the first cases of AIDS were reported in the USA in June 1981, AIDS was regarded as a terminal illness because the continuum of the course of HIV/AIDS was not yet recognized (Molineux, 1997). The Centre for Disease Control (ibid, 1997) classified the four stages of HIV/AIDS in 1986. Stage 1 is regarded as the acute infection stage; Stage 2 is seen as an a-symptomatic stage; Stage 3, the individual becomes susceptible to enduring opportunistic infections and Stage 4 is regarded as the terminal stage of the disease.

During the same period, anti-retroviral drugs (ARV) that slowed the growth of the HIV retrovirus in the body, were developed. Nathanson (2000) in support of retroviral therapy, reported that infected individuals were able to have a better quality and quantity of life when they used antiretroviral drugs. As a result of the possibility of a prolonged lifespan, HIV/AIDS gradually became regarded as a chronic illness (Rabkin & Fernando, 1997). HIV/AIDS shares some similarities with other chronic illnesses but has some unique characteristics too.

The illness is progressive and terminal and alters the individual's state of health and changes the patterns of daily occupations (Pizzi, 1990) as do other chronic, terminal illnesses. A discussion about the unique features of the HIV/AIDS illness will be pursued throughout the next sections.

### **1.1.3 Occupational engagement**

Occupational engagement refers to conditions of living and doing in which “...all essential sustenance and safety needs (are) met, and of having physical, mental and social capacities maintained, exercised and in balance” (Wilcock, 1998, p. 341), regardless of one's illness status. These health-enhancing conditions can be considered to be the occupational rights of all individuals or occupational beings (Wilcock, 1993) in order to be able to experience health. Wilcock (ibid) emphasized that when one of these aspects is absent or unused or not in balance, the individual (or population) may experience ill-health or develop health disorders. I refer to these illnesses as occupational disorders. When an individual or population of persons lacks sustenance needs and lives in a threatening environment they can be coerced (inadvertently) into non-healthy occupations such as alcohol and drug abuse or commercial sex behaviours. The latter behavior may assist them with obtaining monies to buy their daily food for themselves and their families. Thus this population of persons may engage in high-risk occupations that enable survival but promote ill-health because they are not health-enhancing. If one considers that occupations “...are chunks of activity that are personally meaningful and are named by the lexicon of the culture that humans engage in (Clark et al, 1991 p. 303), then engaging in high-risk occupations may not be meaningful, but a necessary occupation for the poor, while they may be labeled as deviant occupations within some societies.

Spencer et al (1996) referred to this occurrence as cultural incongruence. Thus occupational disorders (Researcher, 2002) may develop within enduring living conditions of poverty since the opportunities to engage in health-enhancing occupations may be limited in these circumstances (Wilcock, 1998).

Occupational disorders refer to health disorders developed from the under-use the over-use, or imbalanced use of the human capacities. This includes the individual's physical, mental and social capacities. Occupational deprivation occurs when an individual has limited opportunities to engage in occupations. An individual may suffer from occupational alienation when the occupations he engages in are meaningless to him. Occupational imbalance results when an individual's occupational patterns are not balanced between the occupations that are necessary and those that are meaningful and satisfying (ibid, 1998). Persons living with illnesses also need to exercise their occupational capacities and to adapt, but they may not have the opportunity or resources to do so.

#### **1.1.4 The occupational context**

All occupations are performed within a context that includes other persons, materials, objects, equipment (Du Toit, 1970), a temporal and socio-cultural dimension (Nelson, 1988), as well as the dimensions of spirituality and politico-economics (Kielhofner, 1997). Most importantly, every context has a phenomenological dimension that is defined by a person living in a specific context (O'Connell, 1990). Therefore, each culture constructs its own context that will reflect the dominant consensus of a group of individuals (Frank, 1996) at a specific time.

Thus each culture decides which occupations are valued or available or rewarded and to whom – the well or the ill. This system may discriminate against individuals with specific illnesses by creating negative conditions for occupational engagement and adaptation.

### **1.1.5 The process of health-promotion or occupational adaptation**

Health is considered to be an adaptive response made by a person within a specific context (Law, 1998). Human occupation is one means whereby humans achieve adaptation. This is referred to as occupational adaptation (Schkade & Schultz, 1992; Wilcock, 1998b). Health and the experience of wellbeing through participation in occupation, requires both the capacity for performance of everyday occupations and the opportunity to engage in personal and culturally-meaningful occupations. Frank (1996, p.47) definition of adaptation emphasized that adaptation is not a conscious process and implied that adaptive responses are learned through experience or engagement with the occupational challenge. This view supports an active learning and doing through occupation in order to adapt.

Schade and Schultz (1992) broadened the description of the occupational challenge to include adaptation as a response to challenges arising both internally and externally. For example the occupational need for exercising and developing human capacity as well as the need for adaptation may motivate human engagement in occupation.

Du Toit (1964) stressed the importance of the 'just right' challenge in developing the adaptive capacity of the individual through occupational engagement. She emphasized that adaptive responses have developmental stages and that these required a specific or a "just right challenge" to correspond with the individual's (or population's) level of occupational development.

Although Du Toit's (1970) Theory of Creative Ability and adaptive responses was applied initially to individual clientele within occupational therapy, it is my opinion that this framework may be extrapolated to apply to populations of persons experiencing occupational disorders or who are at risk for occupational disorders for example, people living with HIV/AIDS. The theory views Man as a phenomenological being who applies social agency with the therapeutic assistance of an occupational therapist, to develop his adaptive responses and restore his ability for participation in occupations. The main shortcoming of this theory is that it assumes that social agency exists, namely equal conditions for relating between an ill person and the therapist or by extrapolation, between persons living with HIV/AIDS and their adaptation contexts. The theory also assumes that growth and recovery depend on the therapeutic environment that provides the right challenge and the right support and facilitation. By extrapolation to the non-therapeutic environment, life challenges presented by illness may be too large and outside the range of the adaptive capacity of the person with the HIV/AIDS. The existing context may be unsupportive and hostile so that it discourages occupational engagement towards recovery and adaptation. Unequal power relations may disinhibit or prejudice interrelationships so that the persons living with HIV/AIDS do not have the opportunity to engage in the occupations necessary for their adaptation.

The theory does provide useful guidelines for the quality of the intervention (Du Toit, 1970, p. 7) or enablement (Stewart, 1994) towards occupational adaptation. Perhaps these guidelines can be extrapolated to apply to a normative situation with fathers living with HIV/AIDS, in order to equalize the relations between them and their adaptive contexts.

Illness disrupts occupational development and the engagement in occupations either temporarily or permanently. The HIV/AIDS illness may interrupt occupational engagement intermittently and progressively depending on which stage of illness the person is in, his occupational capacity to adapt to the illness and his relations with the adaptation context.

Occupational scientists acknowledge that occupational responses occur within "adaptive systems" (Clark, 1996, p. 48) that can facilitate or compromise the dimensions mentioned previously. Their unique contribution is their view of adaptive systems that are considered to be dynamic, multi-dimensional and personally constructed (ibid, p. 52). This means that adaptive systems are constructed subjectively by individuals or populations, to fit their particular circumstances.

Schade and Schultz (1992) recognized that occupational adaptation is a process of reciprocation between an individual and the occupational context. Their conceptual framework provides a linear description of the internal process of adaptation and it omits a description of the external adaptation process and the interactive processes of adaptation. This study will contribute to this knowledge by beginning with the identification of the occupational and adaptive context from the perspective of the participants.

## **1.2 The occupational context of HIV/AIDS**

This section examines the pervasive attitudes, conditions of relating and living for persons living with HIV/AIDS from the perspectives of current literature and the researcher. Within the South African context, the HIV/AIDS epidemic is located within a social legacy of segregation, poverty and a lack of access to basic services by the vast majority of the population (Taylor, 1998). Processes of negotiation will therefore be needed to equalize occupational opportunities for healthy living for persons at risk and for persons living with HIV/AIDS (PLWHA).

### **1.2.1 Social Stigma**

The HIV/AIDS illness is unique because the mode of transmission carries a social taboo that reinforces social stigma (Kriner, 1999). This, in addition to the existing negative opportunities for engagement in occupation for persons with illnesses, augments the challenges of occupational adaptation for persons living with HIV/AIDS because access to opportunities for occupational engagement and resources will depend on them disclosing their HIV positive status. For example, in order to access the care required, the person with HIV/AIDS needs to be tested and identified as HIV positive, then he needs to communicate the diagnosis to others to obtain the necessary medical and emotional support. Alonzo and Reynolds (1995) reported that persons living with HIV/AIDS deal with a stigma trajectory that is dissimilar to other illnesses because the stages are unique to this illness and the stigmatization endures throughout the illness.

Thus disclosure during the course of the illness (and accessing care) will be weighed up carefully against the personal costs of

disclosing one's status. Therefore, a necessary part of the illness is managing the ongoing stigma for the duration of the illness.

The course of the HIV/AIDS illness is also more unpredictable than other chronic illnesses and this can impede the working adult's economic productivity and affect the families' living standards or ability to survive because daily consistency in production is an important criterion for working in the open labour market. The South African Government introduced new labour policy to prevent discrimination against persons with disabilities and persons living with HIV/AIDS so that their applications for employment and ability to retain existing employment were equal to persons without disabilities and illnesses (Employment Equity Act, 1998). However, alternatives, such as part-time and session work options are also needed in the formal sector to accommodate fluctuating daily work performances. The clause of 'reasonable accommodation' in the workplace still requires comprehensive definition and implementation. In addition, taking up action against an employer for alleged discrimination requires that one disclose one's HIV positive status privately and publicly. This may be experienced as a greater threat than non-employment.

### **1.2.2 Poverty and HIV/AIDS**

Poverty and HIV/AIDS are closely inter-related because the conditions of living in poverty may pre-empt high-risk occupational behaviours such as drug abuse and commercial sex work, in order for persons to survive from day to day (Kriner, 1999).

Poor health conditions such as poor diet, no running water, poor sanitation and low access to medical care, lowers the immunity to associated illnesses such as tuberculosis (ibid).

In response to 53% of the population of South Africans living in poverty (Ekuseni Trust, 1995), the first democratically-elected government began a poverty restitution program in 1994 which was aimed at providing the basic needs of the poor – including housing, running water, improved sanitation, education and health services. Through this equalization process, the opportunity would be created for poor persons to have their sustenance needs met and to engage in health-enhancing occupations. Non-governmental organizations have continued to lobby for the rights of poor persons living with HIV/AIDS to equal and healthy living. NAPWA (National Association of People with AIDS) recognized the lack of mediating factors such as access to healthy diets, appropriate medicines such as anti-retroviral drugs and social support structures for the poor. As a result, NAPWA has applied pressure on the South African government to provide drug treatment and social grants to poor people living with HIV/AIDS ([www.iafrica.com.news](http://www.iafrica.com.news), February 11<sup>th</sup>, 2002). The BIG campaign (Basic Income Grant) was aimed at coercing the Minister of Finance to introduce such a grant in his Budget Speech presented to parliament on the 23 February 2002 but this was unsuccessful. Poverty alleviation for 53% of the population of South Africa continues to challenge all sectors of society.

### **1.2.3 Political responses to the HIV/AIDS epidemic**

Political responses are not only in flux from day to day but are moderated by ongoing pressure from national and international

political movements with the main aim to provide affordable and accessible drug treatment to all persons living with HIV/AIDS in South Africa. Not only does medical treatment provide hope for living (and a reason for being tested), but by slowing the spread of the HIV retro-virus, anti-retroviral therapy can arrest the progression of the symptoms to AIDS (O'Connell, 1990).

The South African government introduced a National AIDS Control Program to control the incidence of HIV/AIDS (<http://www.hst.org.za/pphc/phila/chapo9.htm>, 4 May, 2002). This program focused on prevention through early education, mass media communications, making the access to barrier methods to prevent sexually transmitted diseases, freely available and providing treatment for opportunistic infections. However, it is difficult to monitor these preventative activities and to measure their results. For example, it is reported that approximately 1,700 new infections occur every day in South Africa (National Department of Health, 1999). In addition, these types of interventions may be more effective within urban areas and semi-urban areas where individuals have access to telecommunication, health education and health provision. These preventative measures may however, not reach the poor who represent 53% of the South African population and who are most susceptible to diseases (Ekuseni Trust, 1995).

#### **1.2.4 Anti-retroviral therapy**

Besides providing medical treatment for opportunistic infections, the South African Government has set up 18 test sites throughout the country where pregnant women who are HIV positive can receive antiretroviral therapy (AZT) to prevent transmission of the disease to their unborn babies. Private organizations such as the Treatment Action Campaign are critical of this service because it

reaches only 10% of all pregnant HIV positive women  
(<http://www.hivandhepatitus.com/navigator>, May, 2002).

The South African Government's attitude towards the provision of anti-retroviral therapy has been controversial and has inspired public and private organizations to defy their stance.

As a result of these efforts, medical doctors may now prescribe Nevirapine at state hospitals, to pregnant mothers who are HIV-positive and to victims of rape. In addition, politicians in the Western Cape have successfully negotiated the free supply of Nevirapine with the pharmaceutical company Boehringer-Ingelheim. They have agreed to supply free Nevirapine for the prevention of transmission in pregnant HIV positive mothers and for rape survivors in the Western Cape over the next five years (Cape Argus, January 25, 2002).

Advocacy groups like the TAC (Treatment Action Campaign) continue to lobby for the free access for all persons living with HIV/AIDS, to anti-retroviral therapy. This organization argues that it is the constitutional right of every citizen to life and healthcare (<http://www.hivandhepatitus.com/navigator>, March, 2002).

Currently, anti-retroviral therapy in South Africa is expensive – an AZT cocktail costs R4,300 for one month's treatment. Therefore anti-retroviral therapy can only be accessed by persons who volunteer to participate in clinical trials and those with Medical Aid's or who can afford the drugs. The South African Government has refused to make anti-retroviral drugs available for every person living with HIV/AIDS citing theoretical arguments about the unestablished link between HIV and AIDS as well as the threat of potential toxicity of the anti-retroviral drugs. By controlling the availability of these drugs however, they inadvertently reinforce the stigma of blame around HIV/AIDS as a disease caused by immoral behaviour or deviant lifestyles that necessitate non-treatment.

The fears around contagion will be maintained when individuals perceive that there is no treatment for a disease. The attitude of blame that is reinforced through non-treatment, limits the ability of all persons to engage with the care systems that could facilitate adaptation and promote healthy living because they will fear being ostracized by partners, families and communities (In personal communications with Sr Fielder, 20<sup>th</sup> June 2001). This sets up a condition of non-engagement with both the opportunities and available resources for occupational adaptation.

### **1.2.5 The response of Occupational Therapy to the HIV/AIDS epidemic**

In this section I discuss trends within occupational therapy practice that overlap with the conceptualization of occupational adaptation as used within this study. This part of the literature review will identify the cause and course for a qualitative study concerned with describing the experience of occupational adaptation for fathers living with HIV/AIDS from the perspective of the fathers.

#### **1.3.1 Background**

Occupational Therapy is a rehabilitation science that aims to enable individuals and populations to engage or re-engage in their everyday occupations, following a change in health and life circumstances or when they experience discrepancies in their occupational development (Wilcock, 1998). Occupational therapy continues to be embedded in the philosophy of holism and humanism in spite of an over-emphasis on a medical view of health that has persisted over the past few decades of practice.

During this time, quantitative research and reductionism (Stewart, 1994) preoccupied the occupation of occupational therapy. This resulted in an over-prescriptiveness and an over-focus on discrete outcomes in occupational therapy theory and practice.

The development of the discipline of occupational science was an important movement in redirecting occupational therapists to their roots of holism and humanism through stimulating qualitative research based on enquiry and the subjective perspective's of health consumers. In this manner, occupational science has been instrumental in restoring the qualitative aspect of occupation in occupational therapy philosophy and practice i.e. a refocus on the meaningfulness of occupation in occupational therapy, to occupational therapists and to health consumers. This has directed clinicians towards client-centered practice.

Another consequence has been the recognition of the neglect of the rights of all persons who are at risk for or with illnesses, to equal and healthy living. This awareness raised a consciousness about the moral responsibility of the profession to the democratic principles of equality and equity and has promoted the theoretical expansion of the role of the clinician from medical-based practice based on normalizing function, to a social-rights practice based on equalizing opportunities (Wilcock, 1998) for promoting healthy contexts for occupational adaptation. The common aim amongst adaptation contexts within a democracy is the achievement of a balance between occupational needs, opportunities for occupational adaptation and a given level of resources that need to be distributed fairly. This requires an eco-systemic framework where all elements and factors are balanced in an interdependent manner.

Qualitative enquiry will contribute to identifying what constitutes the adaptive systems for an individual or population from the perspective of the individual or population. The subjective perspectives will inform one about the parameters of the adaptive systems as experienced by the individual or population.

### **1.3.2 Occupational Therapy trends pertaining to the HIV/AIDS illness**

Written publications on occupational therapy practice with clients with HIV/AIDS illness commenced almost two decades ago in America and these and others by British and Australian authors have continued to be written within a western perspective of health service provision focusing on curative services and preventative services more recently. In addition, Yallop (2000) identified three phases in the changing identity of the person living with HIV/AIDS as a direct result of medical intervention: from a person living with HIV/AIDS or an acute life-threatening illness, to a person living with HIV or a long-term chronic condition (Lowth et al 1999a), to a new emerging non-illness role. The occupational therapy interventions have followed this changing HIV context, providing support to the first two phases while my research study provides support also for the third phase.

In the early eighties when AIDS became an identifiable illness because the symptoms and signs were visible, persons with AIDS were referred for occupational therapy. The occupational therapy interventions were initially aimed at adjustment of occupational roles and dealing with losses within the experience of terminal illnesses (Tigges & Sherman, 1983; Pizzi, 1984).

Within the illness-welfare model of care (Lowth et al 1999a, 1999b) services for basic daily requirements such as food, financial assistance, housing, income support, home help and transport were provided. PLWHA central occupation became 'being HIV positive' (Yallop, 2000, p. 422). This entailed "*the tasks of attending medical appointments, counseling and physiotherapy/fitness; dealing with social services and social workers and housing issues; volunteering for AIDS organizations, taking medications, being an AIDS activist and reading multitude of HIV literature; attending HIV social gatherings, peer support groups and information sessions; and caring for lovers and friends who were dying*" (ibid, p.423).

During this time, occupational therapist's developed guidelines for occupational therapy intervention with clientele with AIDS (Caestle, 1986; Denton, 1987; Guiles & Allen, 1987). The guidelines included precautions to be taken when working with individuals with HIV/AIDS such as infection control and other safety measures. The authors recommended core rehabilitation strategies for the terminal phases of the illness such as education, making physical and psychological modifications and dealing with termination.

Bonck (1987) considered neurological treatment issues for occupational therapy and Gonzales (1988) highlighted the role of collaboration in working with clients with AIDS. Schindler (1988) provided an overview of psychiatric symptoms in adults with AIDS using an occupational behaviour frame of reference. He made reference to the vulnerability (within the first 100 days of diagnosis) to the experience of reactive symptoms such as depression, anxiety and preoccupation with the illness. This finding is supported in a local study that showed that most decline

in function occurred early in the disease during Stages 1 and 2 (O'Keefe & Wood, 1996). Schindler citing Pizzi (1984), advocated psychosocial interventions to enhance the quality of life of the person with AIDS by assisting them to develop skills, set priorities, maximize occupational roles and to gain a sense of mastery and competence over the present environment, the self and the disease process.

Pizzi (1990) argued for a total program of care for adults with HIV and AIDS to include not only the physical and psycho-social aspects but also the environmental needs of these persons and their caregivers. For example the social environment needed to include the partner/family's needs to care for the client and thus to incorporate their support of the client. Pizzi continued to apply various modes of interventions with HIV and AIDS clientele between 1987 to 1990 (Pizzi, 1988; Pizzi, 1989a; Pizzi, 1989b, Pizzi, 1990). In 1990, Pizzi published a practice model utilizing the Model of Human Occupation, as applied to clientele with HIV and AIDS.

The American Journal of Occupational Therapy devoted a whole journal issue to HIV/AIDS in 1990 (American Journal of Occupational Therapy, 1990, Volume 44, No 3). This included statements about the need for occupational therapists to develop compassionate attitudes by becoming well informed, and taking necessary precautions.

The issue also discussed various intervention strategies for children and adults living with HIV/AIDS. In the same journal, Weinstein & De Neffe (1990) discussed occupational therapy intervention with clients with hemophilia who contacted AIDS.

They recommended the following rehabilitation strategies: stress reduction, anger management, communication, energy conservation, educating families and helping them to set goals, designing adaptive systems for dealing with neurological deficits and designing exercise programs.

In the same year, Weinstein (1990) applied the Sickness Impact Profile test to clientele with HIV/AIDS in order to measure their health status in stages 3 and stages 4 of the disease (symptomatic) and the corresponding occupational areas in which most dysfunction was experienced. They found that the highest dysfunctions were experienced in work, leisure, cognitive and emotional behaviour.

While the knowledge about causal factors increased to include mother-to-child-transmission, Anderson et al (1990) discussed occupational therapy for children with peri-natal HIV infection. These interventions were focused on offering holistic treatment and providing for their psychosocial needs by maximizing environmental interactions that are pleasurable to the child and this included working with caregivers to enhance caregiver-child interactions.

The role of the occupational therapist in maintaining the health of the client with HIV, throughout the four stages of the HIV/AIDS continuum, is the focus of an article by Coates & Barratt (1990). The authors emphasized the importance of occupational therapists being well informed in order to care for the client with compassion. This required a listening response and a consultation approach.

In the same year Pizzi & Johnson (1990) published a handbook for health professionals, entitled: *Productive living strategies for people living with AIDS*. The book is a collection of multi-disciplinary strategies to enable active living for clients with HIV/AIDS particularly in Stages 3 and 4 of the illness.

Occupational therapy contributions include energy-conservation strategies, the strategy of meaning-creation and collaboration with the family.

While the fears of transmission risks in working with clients with HIV/AIDS continued, Bedell & Kaplan (1996) wrote a Position Paper for the profession in order to correct mis-information and to encourage occupational therapists to accept increasing referrals for clients with HIV/AIDS. Molineux (1997) outlined a continuum of service provision for occupational therapists working with PLWHA during Stages 1-4. He suggested educational and psychosocial interventions aimed at stages 1 and stage 2 of the HIV/AIDS illness, to add to the repertoire of an occupational therapist's skills. Molineux (ibid) identified restrictions in occupational therapy interventions and directed occupational therapists towards a practice model based on enablement and empowerment within multi-contexts in order to serve the needs of PLWHA.

Fish and Rudman (1998) cited in Yallop (2000) discussed the potential role of occupational therapy in the acute care with clients with HIV/AIDS. They emphasized positive attitudes towards PLWHA and included a brief discussion on sexuality issues.

Lowth et al (1999b) cited in Yallop (2000), identified the changing needs of the population of PLWHA as a result of having a prolonged lifespan and changing occupational needs. The authors challenged health professionals to adapt their services accordingly.

Nearly two decades after occupational therapists began working with clientele with HIV/AIDS, McVey et al (1999) cited in Yallop (2000) reviewed occupational therapy practice and theory in the field of HIV/AIDS (I was unable to obtain this publication). Yallop (1999) in recognizing the changing occupational needs of PLWHA, facilitated a Positive Employment Service for these clientele in Northern Sydney. The following year, she considered the pertinent role of the occupational therapist in assisting PLWHA to deal with expanding identity and sexuality issues (Yallop, 2000).

Within the new, emerging identity of the PLWHA as an occupational being and not a person living with HIV/AIDS, Bedell (2000) was the first occupational therapist to use qualitative research methods to explore and describe the daily life of eight urban gay men from the perspective of the men. Molineux (2001) similarly, commenced his research on the occupations of men with HIV/AIDS from the perspective of the men.

I was unable to find information about occupational therapy practice with clients living with HIV/AIDS in South Africa. I considered it important to understand the occupational context and the adaptive systems in which the illness experience occurs for persons living with HIV/AIDS in South Africa, in order to reduce their risks for occupational disorders and to facilitate their occupational adaptation within a local context. Alternatively, I considered the importance of identifying potential adaptive occupations that were being used successfully by fathers living with HIV/AIDS, because these could guide appropriate occupational therapy interventions.

### **1.3.3 Occupational therapy interventions with parents and fathers.**

Parental occupations include socializing children, nurturing and protecting them. Each society however, places different values on the various dimensions of parenting and these may vary over time. For example, some societies may focus on the provider role that has a strong gender focus towards males traditionally (Barclay & Lupton, 1999). Contemporary western societies however, tend to expect the male parent to care for and nurture the children too (ibid). Traditional gender role expectations are diminishing as parental occupations become more complementary, with both parents sharing and interchanging parental occupations according to their availability (Hanson & Bozett, 1986; Tiedjie & Darling-Fisher, 1996; Barclay & Lupton, 1999). The demands of these changing roles "... *challenge men's relationships with their female partners, the meaning and place of work in their lives and their sense of self as competent adults*" (Barclay & Lupton, 1999, p.1013).

South Africa consists of many diverse cultures. Some of the traditional cultures may have retained their nuclear family constellation while others may have changed. One-parent households may be more common. This means that the parental tasks will be performed by one parent only, with some sharing of tasks amongst partners, friends, family or neighbours. These socio-cultural changes will influence and change what the parent does and how he does it. This challenges the profession of occupational therapy in South Africa to be directed into research based on scientific enquiry methods that describe occupations and occupational adaptation from the perspective of a parent.

Llewellyn (1994) posed the question about the neglect of parents' views about their own parental occupational performance within occupational therapy literature.

Fathering in occupational therapy is usually viewed within the framework of role theory (Jackson, 1998): adult males are socialized to perform certain roles that they aspire to when they become parents and their competence as a parent is evaluated accordingly. In an attempt to reduce role stereotyping and to facilitate social agency, Townsend (1999, p. 58) referred to fathering as all the things people do when they are "*doing fathering*". This may include elements of enjoyment, caring, nurturing and training.

Traditionally, occupational therapists facilitated parental competence when parents needed to manage a child with a disability, by enhancing their parental skills (Bazyk, 1989) and by engaging them as a professional partner (Llewellyn, 1994).

Research studies published in the last five years has begun to address the mothers' views and experiences of parenting when managing a child with a disability (Pierce & Frank, 1992; Larson, 1996; Segal, 2000; Olson & Esdaile, 2000; Larson, 2000).

Whilst this knowledge is important in addressing the impact of the child's disability on the performance of the parental occupations of the mother, the studies have not considered the separate experiences of the father when he parents a child with a disability.

More importantly, the international and national literature has not considered the experience of being a father with HIV/AIDS and how this impacts on the occupations of fathering. It is necessary to understand fathers' experiences of the illness and which conditions of living facilitate or hinder their occupational adaptation and their ability to continue fathering.

## **1.4 The experiential origin of the study**

This section describes the rationale for the study as it originated from my personal and professional experience with the phenomenon of occupational adaptation.

### **1.4.1 Interpreting theory**

My understanding is that health and well-being are possible in a society where there is coherence between a person and a culture's capacities, occupational needs and the conditions of living or relating. Achieving coherence between these three factors is the aim of occupational adaptation. Occupational adaptation is a process in which individuals construct their own adaptive systems for development and growth (Frank, 1996, p. 51). According to Frank this is done by "*organizing material and human resources and establishing flexible routines*". Thus fathers living with HIV/AIDS need to achieve this occupational coherence in order to be able to adapt and to continue their fathering occupations.

Occupational adaptation may however, be hindered by relation imbalances amongst these three factors for example, the absence of human and material resources for the poor prohibits engagement in occupation for adaptive and health purposes. In addition, positive interrelationships between these three factors, promotes conditions for adaptation while negative relations between them inhibits adaptation by setting up negative conditions for relating/negotiating and living. It is not known what adaptive systems fathers with HIV/AIDS utilize, nor the quality of these interrelationships. It is assumed that negative relations such as social stigma, disparities in skill and economic development

as a result of poverty, will hinder occupational adaptation because it sets up conditions of living and relating that restrain the ability and opportunity to adapt through doing and to interact with the environment. Positive relations in contrast, encourage interactions by developing infra-structures that promote access (implying acceptance and cultural congruence) and also promotes occupational adaptation. Fathers with HIV/AIDS may experience a reduction in occupational capacity and a reduction in opportunities for occupational engagement due to the illness and it is not known what adaptive systems they utilize and how effective they are.

#### **1.4.2 Encounters as an occupational therapist**

I work in a Work Assessment Unit as an occupational therapist, where I assess people's current work-ability for accessing employment in the open labour market. The majority of these clients experience a lack of health and well-being that appears only partially related to their physical or psychiatric disability. They discuss lack of opportunity for paid work in the formal sector results in living in poverty. They also report that loss of the masculine role of provider results in a loss of a sense of purpose and identity.

These clients need their transport monies to the Unit to be funded by the Unit because they are unable to afford them. Frequently, they do not take their medicines because they do not have food to eat before taking their medicines. They have no lunches and unless provided by the Unit, they will continue working a 5-6 hour shift without sustenance.

For the majority of clients, the primary motivation to attend the Work Assessment Unit was to be able to obtain monies for basic living for their families, in the form of a disability grant (currently R630.00 per month). This figure is considered to be below the minimum living wage for a family (May & Govender, 1998). However, it is the only viable source of income for the poor because the majority of clients have limited skills or are unskilled to work in the open labour market under the current standards of employment. Some clients living within the same conditions of poverty were able to mobilize themselves, their families and communities to engage in informal, paid employment. These clients appeared less stressed and better adapted, engaging in personally-meaningful occupations in spite of their disability and impoverished conditions of living.

My observations led me to believe that the fathers' role as sole breadwinner for the family is still valued strongly within some communities in Cape Town. An inability to meet the requirements of this role placed the individual and the family at a high risk for occupational disorders because there were no mediating factors for alternative financial assistance to meet their sustenance needs. I questioned why some fathers made adaptations and how this was facilitated. I also questioned the traditional role of the occupational therapist as a facilitator of personal capacity for occupation and the potential role of facilitator of adaptive capacity through adaptive occupations. I considered whether the occupational therapist did not have a moral responsibility to advocate for improved conditions of living for our clients? In this manner, she could create positive conditions for occupational adaptation.

### **1.4.3 Personal experience**

My personal experience (and therefore expectation) of the male role is that they fulfill the primary role of main breadwinner within a family. I have also observed this phenomenon within many cultures in the past and in the present. It is only in the event of illness, death, disability or divorce that there may be a role reversal and the single partner may assume this role for survival purposes. I wondered about the personal and cultural meaningfulness of this role for the father and whether their health may be disadvantaged or constrained by lack of exploration and development of other roles and occupations. I also wondered about society's attitude on potential changing male occupations. For example, would labour policy support such an occupational development trend?

### **1.5 Developing a focus**

The insight generated through reviewing the literature and the above experiences resulted in the following problem being formulated:

*“Males identify strongly with the role of provider whether poor or ill or disabled. Fathers with HIV/AIDS are vulnerable to prolonged, progressive periods of formal unemployment because of the nature and course of the illness as well as market conditions of high unemployment, that make it difficult to enter or re-enter the employment sector. The problem is exacerbated by HIV/AIDS illness because there will be progressive but unpredictable fluctuations in the individual's capacity for formal work.”*

*The absence of mediating factors such as financial alternatives or working condition alternatives, mitigate against adaptation and recovery. In the absence of having their basic needs met, the father, their families and communities are unable to participate in occupations that would assist their adaptation. This places fathers and their families at risk for occupational disorders and other health disorders. In the absence of mediating factors, fathers will be unable to develop their adaptive capacities for healthy living. They will also be unable to continue their fathering occupations.*

I began to investigate the possibility of conducting a study based on the above problem statement. I aimed to focus on fathers' with HIV/AIDS experience of occupational adaptation by describing his daily occupations.

**CHAPTER 2: METHOD OF ENQUIRY**

University of Cape Town

## CHAPTER 2: METHOD OF ENQUIRY

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### **2.1 Problem statement**

Fathers with HIV/AIDS are vulnerable to a disruption of their fathering occupations. This may limit their opportunities to develop their adaptive capacity that is developed through participation in fathering occupations.

### **2.2 Aim of the study**

This study aims to explore fathers' with HIV/AIDS experiences of fathering and their experiences of occupational adaptation through their engagement with occupations of fathering.

### **2.3 Research question**

What are fathers' with HIV/AIDS experiences of engaging in fathering occupations?

### **2.4 Research objectives**

The research aims were translated into the following objectives:

- a) To describe the experiences' of fathers with HIV/AIDS
- b) To describe the fathering occupations of fathers with HIV/AIDS

- c) to identify the meaning they attribute to their engagement in fathering occupations
- d) To identify the purpose of these occupations for them and the adaptive function they serve

## **2.5 Choice for method of enquiry**

The research question posed can be classified as qualitative-phenomenological because it is concerned with father's with HIV/AIDS perspective of their view of their own illness experience and how it impacted on the fathering occupations. Thus the question is posed about a specific phenomenon namely, *the experience of fathering by fathers living with HIV/AIDS*, as interpreted by the father's living with HIV/AIDS.

## **2.6 Phenomenology**

Descriptive phenomenology as a qualitative research approach, involves describing accurately the individual's experience of phenomena. This experience includes "*what one perceives, and knows in one's immediate awareness and experience*" (Moustakas, 1994, p. 26). The experience is embedded within a specific socio-cultural context (Finlay, 1998). The individual's subjective experience of phenomena is regarded as authentic and is based on a socially-constructed reality (ibid, 1998). This enables the researcher to discover what an individual's interpretation and thoughts are regarding a specific experience.

## **2.7 Phenomenology as a method of choice**

This study aims to explore and describe the fathers' with HIV/AIDS experience of fathering. To do this, the researcher aimed to understand what they perceived their fathering occupations to be, and, within the illness experience, what the challenges were and how they managed these through occupational adaptations in order to be able to continue fathering. This matched well with the phenomenological approach because it allowed the researcher to explore the individual's interpretation of these phenomena.

## **2.8 Data collection within Phenomenology**

The aim of the phenomenological approach is to learn about phenomena viz the phenomenon of fathering for fathers' living with HIV/AIDS. For this purpose, the researcher needed to utilize personal reflexivity and methodological reflexivity (Finlay, 1998). This would enable a responsive yet impartial interpretation. Personal reflexivity entailed the continual evaluation of subjective responses of the researcher and included the researcher's assumptions, expectations, emotional reactions and unconscious responses. Methodological reflexivity refers to the continual evaluation of the subjective responses that impinge on the method of research. The former was achieved through bracketing and the latter through the use of a reflexive journal (Lincoln and Guba, 1985).

## **2.9 Bracketing**

This term refers to the method used to identify my personal assumptions and pre-conceptions about the phenomenon in the study in order to make my biases explicit (Munhall, 1994). For this reason, I was interviewed by my project supervisors. These interviews required that I reflect on and record my past experiences with fathers and explore my motivation for pursuing this research topic. The interviewing process initiated self-examination that is necessary for a reflexive research process.

I kept a journal of my experiences and feelings throughout the data collection and data analysis stages. This was a method of self-debriefing that enabled me to separate my experience from the experience of the participants'. Bracketing during the data analysis stage ensured that I was able to gain as unbiased interpretation of the data as possible.

Through this process of reflexive journaling I was able to critically evaluate my perspective to determine how I might have influenced data collection and data analysis in the study. Reflexivity was further achieved in discussion with supervisors and colleagues throughout the research process. Finlay (1998) stated that when reflexive analysis was made explicit by being open to public scrutiny, the trustworthiness of the study could be increased. This reflexivity was further supported by the techniques used to ensure the credibility or trustworthiness of the study.

## **2.10 Gaining access to participants**

The subject of enquiry was a sensitive one and my enquiries about gaining access to participants for the study was met with varying responses. Some organizations responded with extreme over-protectiveness with no consideration for accessibility while other organizations were over-enthusiastic about the opportunity for complementing their socio-political agendas. I selected a health context that offered equal access on the assumption that they had experienced the need for persons living with HIV/AIDS to share their stories. This HIV Research Unit was situated at a hospital and the "patients" were participating in clinical trials. It was thought that within a context of established confidentiality, the establishment of trust between the researcher and the participants would be facilitated. This would increase the researcher's understanding of the participants in the process (De Ploy and Gitlin, 1994) and contribute to developing the relationship between the researcher and the participants.

## **2.11 Sampling**

This refers to the manner and purpose of selecting participants for the study. For the purposes of this study, I selected purposive sampling (Holloway & Wheeler, 1996). This is a method of selecting participants who matched the sampling criteria and the purpose of the study. The participants were also required to be "good informants" who were willing to share their stories and to reflect upon their experiences. The senior nursing sister at the Research Unit assisted me in identifying suitable participants, after explanations of the sampling criteria.

### 2.11.1 Sampling criteria

The participants were fathers with HIV/AIDS who:

- a) were engaged with clinical trials at the Research Unit
- b) lived in Cape Town and surrounding areas
- c) could communicate in English or Afrikaans
- d) were between the ages of twenty to thirty-five years. I assumed that this group of fathers would have at least one child.

### 2.11.2 Evolution of sampling criteria

To include participants who were suitable for the study and were information rich, I decided to make a concession with two criteria and to discard one criterion from the initial sampling criteria. These are discussed below.

**I made the following concessions :-**

- a) The criterion *that participants live in Cape Town* was extended to include ***Cape Town and surrounding areas*** in order to include an information-rich participant in the study.
- b) The criterion *that participants must be able to communicate in English* was extended to include ***English and Afrikaans*** because two of the participants were unable to express themselves well in English. Since I had a good understanding of the Afrikaans language, it was unnecessary for a translator to assist with the interviews. However, to enable accurate transcribing, I arranged for an Afrikaans-speaking transcriber and an Afrikaans-speaking and Cape Town - colleague, to assist with the written translations.

**I discarded the following criteria:**

***Participants should have children in primary school.***

This criterion was included initially to ensure that fathers had a given period of fathering experience. I reasoned that diverse periods of fathering would provide a more enriching description. After discussions with the Research Unit's senior nurse, I decided to include one participant with a younger child because he was potentially information –rich and would thus make a significant contribution to the study. Hycner (1976) reported that it is important that participants have the ability to reflect on and describe their experiences coherently.

**2.11.3 Sample selection**

Three persons who met the sampling criteria, were selected for the study by myself and the senior nurse at the Research Unit. The small sample size of three participants is acceptable for this type of research because it allows an opportunity for a thick description (Gertz, 1973) and in-depth understanding of the participant's experience. Information redundancy is the main criterion for size of sample selection (Lincoln and Guba, 1985). Saturation was obtained during the second interview when no new information emerged. In this type of research the participants are included until no new information is obtained.

**2.11.4 Participating in clinical trials at the Research Unit**

In order to qualify for the clinical trials at this Unit, persons with HIV/AIDS need to be interviewed, counselled and their illness staged – persons in Stages 2 and beginning stage 3 are accepted for clinical trials. This meant that these participants were in the

asymptomatic stage and entering the symptomatic stage of stage 3. Thus the illness would not be visible yet. In addition, transport cost's were funded by the Research Unit. Without this funding, the participants would have been unable to access the service.

## **2.12 The data collection procedure**

This procedure entailed preparing the context for the interviews and choosing a suitable qualitative interview technique for collecting the data.

### **2.12.1 Preparing the interview context**

I was invited to attend the Research Unit on the same days as the potential participants. This enabled the nursing sister to inform them of my study and if they expressed an interest to participate, they were then introduced to me. Following this procedure meant that their autonomy and their confidentiality were respected. In turn this reinforced their trust of the clinic and the researcher. These two factors are critical in setting the tone for participation in the interviews, particularly in view of the participant's preference for lack of or selective disclosure to others.

Meeting the potential participants in a context of confidentiality made them feel safe and anonymous and enabled them to participate in the study. Setting up this type of sensitive context impacts positively on the quality of data collected (DePoy and Gitlin, 1994).

All the interviews were conducted in the Research Unit that is a familiar setting to the participants. An improvised private office within the clinic was used for the interviews and the clinic arranged for drinking water and a heater to be made available for the course of the interviews. This contributed positively to a caring and confidential atmosphere for the interviews.

At the beginning of each meeting, the researcher explained the purpose of the study to the participant. It was described as a study that would explore ***what it is like to be a father living with HIV/AIDS***. The researcher gained their permission to participate by asking them to complete a consent form (see Appendix A). The interview was initiated once the participant gave his consent.

### **2.12.2 The interviewing technique**

I selected to use a Free Attitude Interview (F.A.I.) (Oskowitz et al, 1998) format for the interviews. This is characterized as a "*person to person method to obtain information concerning an opinion, while the interviewer is non-directive*" (ibid, 1998, p. 2). Such an interview entails asking one question. The main question was: **What is it like to be a father living with HIV/AIDS?** The interviewer may not ask new questions. She may however, use specific techniques to summarize, reflect, stimulate and ask for clarification of the given information (ibid, 1998). The interviewee is allowed to talk about anything as long as it is within the framework of the starting question.

The essential qualities required for this kind of research are the ability to listen, to follow cues and to structure the information after it has been given (ibid, 1998). These techniques facilitate the flow of the interview.

When this type of interview is conducted well, the interview may be experienced as a conversation with a purpose for the participants (Hycner, 1985). In order to promote the conversation, I decided to have the following sub-questions and to use them if required. The questions were: *“What are the things you do everyday?”* and *“Has anything changed since you’ve had the illness?”*

I prepared myself for the interviews by reflecting on the primary question and the research aims, as well as practising the various interview techniques used for reflection during the interview. This enabled me to keep a clear focus during the interview while listening actively. It also enabled me to be aware of the nuances of cultural habits and emotion, which in turn encouraged fuller participation. For example, within some African cultures, it is considered to be respectful for males and females when talking, to avert their gazes and not look at each other directly. Hence the chairs for the interviews with one participant were rearranged.

To reduce the concerns for transport costs, the participants were interviewed on the same days as their routine visits to the Research Unit. The participants were interviewed individually for two forty-five minute sessions i.e. a total of ninety minutes each. The second interviews occurred one month later and the group interview occurred in the third month after the first interviews had commenced. In the third interview, I interviewed the group of participants for an additional forty- five minutes. This was a member-checking interview (defined below).

### **2.13 Trustworthiness and rigor**

Trustworthiness refers to the documented assurance given by the researcher to the reader about the credibility of a qualitative research study. This involves recording the audit trail followed

throughout the research so that the reader can follow the decisions made throughout the process to its final conclusions (Rogers & Cowles, 1993).

### **2.13.1. Credibility**

Lincoln and Guba (1985) proposed techniques for ensuring the credibility of a study and for establishing the truthfulness of the findings to the participants. In this study, techniques of member checks, peer review criticism and triangulation, were utilized to ensure the accuracy of the findings.

#### **Member checking**

This technique involved examining data with the participants to see if the data represented their experiences truthfully (Lincoln & Guba, 1985). Colaizzi (1978) recommended that the exhaustive description be presented to them for comment because it will be more easily recognizable to them. This was done during the second interview with each participant. Here the members were able to clarify points that they felt were poorly presented while confirming other descriptions and explanations about the experience of fathering. During the final meeting (the group interview), the initial interpretations and possible conclusions were discussed with the members. The researcher also discussed the categories and sub-categories of the analysis with the participants. The participants verified that the analysis and conclusions were accurate. Within this group meeting, the members shared new information about the extent of their feelings of guilt and self-blame for transmitting the virus to their partners and their guilt about commencing with anti-retroviral therapy before their partners did.

Lincoln and Guba (1985) refer to the incremental effects of prolonged contact between the researcher and the participants, during which different information may be volunteered. In addition, I interpreted the timing chosen to share this information, to mean that some aspects of the guilt- experience were more sensitive and thus easier to share in the presence of other males with similar experiences.

### **Peer debriefing**

This refers to the process of presenting the data analysis and conclusions to peers and supervisors for critical evaluation. Different parts of the study were presented to the University of Cape Town Occupational Therapy Post-graduate Research Forum for discussion. These discussions provided me with new insights and confirmed the appropriateness of the conclusions. The discussions with my supervisors enabled a critical analysis of the data and relevant interpretation of the findings.

### **Triangulation**

Triangulation requires the use of three different sources to verify the data. In this study, this was achieved through the interviews, literature and contextual documentation. This included information provided by the senior nursing sister at the Research Unit, my journal and information from the news media (Rodgers and Cowles, 1993).

### **2.13.2 Transferability**

Lincoln and Guba (1985) stated that this concept referred to the way findings may be transferred from a representative sample of the population to the whole group. This study aimed to describe the fathers' with HIV/AIDS experience of fathering. The aim was not to generalize the findings to the entire population of fathers with HIV/AIDS. However, the decision trail implemented in this study has been clearly detailed within this report. This detail enables the reader to consider how much of the findings in the study could be true for similar groups.

### **2.13.3 Dependability**

This concept refers to the consistency of findings and is based on the credibility of the study. Therefore if a study is credible, it will also be considered dependable. The dependability of this study is enhanced by the thick description of the theory, methodology and analytical choices made throughout the study (Krefting, 1996). These choices are made explicit throughout this report.

### **2.13.4 Confirmability**

In this report I have provided thick descriptions (Gertz, 1973) in the discussion on the concepts, theory and method of enquiry. These allow the reader to follow the manner in which the study was conducted and to clearly follow the research process to the conclusions that are reached.

## **2.14 Ethical considerations**

Specific research principles are applied to ensure the rights of individuals to autonomy, non-harm, beneficence and justice (Munhall, 1994). These principles were upheld in this study as follows:

### **2.14.1 Obtaining consent for recruiting participants**

The Head of the HIV/AIDS Clinical Research Unit was approached for permission to recruit participants for the study. This was obtained in May 2001.

### **2.14.2 Obtaining informed consent from participants**

Voluntary consent was sought from the participants by providing information about the research title, purpose, process and outcome to them. An approximate time frame of three months was also stated. The participants needed to know what would be expected of them and what the benefits and possible risks involved in participation in the study entailed.

The participants understood the purpose of the research and I explained that copies of the report would be made available to the Research Unit, to the University of Cape Town and that parts of it would be published in journals. The participants were informed about the potential personal benefits of increased self-awareness as a result of their involvement in the study. I was not able to provide a financial payment for their involvement in the study, although one participant requested this.

The participants raised concerns about their transport fees and it was explained to them that their interviews would be scheduled to coincide with their routine visits to save costs and that the Research Unit would continue paying the transport costs for their routine visits to the hospital.

I informed the participants that they were allowed to withdraw from the study at any stage. This information was included in the written consent form (Appendix A). It was explained to them that withdrawal from the study would not prejudice or impact on their treatment at the Research Unit.

### **2.14.3 Sensitive Information**

The participants were alerted to the sensitivity of the information and corresponding feelings of vulnerability that they might experience (Oskowitz, 1997). During the interviews I remained sensitive to their feelings by responding to cues that enabled me to support their emotional expressions whether expressed covertly or overtly. I was careful not to probe for information that was unrelated to the research question. I also informed them that a nursing sister was available for counseling between the interviews.

### **2.14.4 Confidentiality**

Confidentiality is the undertaking by the researcher to disclose only what the participants wish to have disclosed and to keep their identities anonymous. Within the HIV/AIDS context the need for confidentiality and anonymity is heightened. In this study the participants preferred me to use only an initial in the written report.

The participants' consent was obtained to audio-tape the interviews, after explaining that the purpose was to enable verbatim and accurate transcriptions. It was made explicit that the recordings would only be used for this report and that the audio-tapes would be destroyed after the report was submitted to the university for evaluation. During the research process the tapes were stored in a safe and secure place.

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**CHAPTER 3: DATA ANALYSIS**

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## CHAPTER 3: DATA ANALYSIS

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### **3.1 The process of data analysis**

This involved the following steps: data management and thematic analysis.

#### **3.1.1 Data Management**

The interviews were transcribed verbatim into the language used during the interviews i.e. two Afrikaans and one English, by a person who was well experienced in transcribing in both languages. The data was managed manually using a cut-and-paste method by hand for the coding process.

#### **3.1.2 Thematic Analysis**

Giorgi (1975) emphasized that the research method and method of data analysis needed to be complementary and to arise in response to the phenomenon being studied. For this reason, guidelines for a phenomenological analysis of interview data as outlined by Hycner (1985) were followed in this study.

#### **The first phase of the thematic analysis**

The interviews were tape recorded with the consent of the participants'. Immediately after the interviews, I made a second copy of the tapes so that I could listen to them and make preliminary notes while the original interview tape was taken to the transcriber. The experienced transcriber contracted verbally to

maintain confidentiality about the information on the tapes and she was encouraged to raise questions with me only.

The interview tapes were transcribed by an Afrikaans-speaking person, who was well experienced in transcribing in the Afrikaans and English languages. We developed a notation system to indicate "*para-linguistic*" (Hycner, 1985, p.280) communications, including pauses. The transcriptions were completed immediately after the interviews, giving me time to read and understand the first interview data before the second interviews took place.

In an attempt to bracket my presuppositions about the interviews, they were discussed with a supervisor and recorded in writing. In order for me to get a sense of the whole interview or gestalt (ibid, p. 281), I both listened to the same tape and read the transcription of the tape a number of times to be able to pick up the non-verbal and para-linguistic communications.

### **The second phase of thematic analysis**

This involved identifying units of general meaning (codes) whether they are relevant or not to the phenomenon experienced. Thereafter, only units of meaning that were relevant to the research question were retained. These meaning units were discussed with colleagues to verify the developing analysis.

The next step was to cluster units of relevant meaning together within the context of the interview. These clusters of units or categories were numbered and the relevant meanings recorded beneath them. The same process was followed in developing first the categories and then the themes for the individual interviews. At this stage it was important for the researcher to obtain a sense of the whole and to provide a context for the emergent themes.

An early “validity check” (Hycner, 1985, p.291) was made by checking the data of the first interview with each participant during the second interview. This enabled the participants to engage in a dialogue with the researcher about the summary and emerging themes. This also provided them with an opportunity to add further information to that already gathered. I generally found that the participants agreed with the emerging themes and because it was our second meeting, were eager to add more emotive information about their experiences verbalized in the first interview. This new information was absorbed into the data from the first interviews for each participant using the same inductive process.

### **The third phase in thematic analysis**

The next step required that I identify common themes across all the interviews as well as individual variations. These would set the parameters of the themes. At this point, I approached the University of Cape Town Post-Graduate Research Group for validation of these common and divergent themes. This discussion provided me with increased insight and also validated the emerging unique and general themes.

### **The final phase in thematic analysis**

The final step involved analyzing the themes within the context of the individual experiences and then assimilating them into the overall context of the experiences of fathering by fathers' with HIV/AIDS. The final analysis was discussed critically with supervisors who provided increased insight about the final themes.

**TABLE 1**

<b>THEME 1: THE CRISIS OF LIVING — YOU GOT NOTHING REALLY IN YOUR HAND</b>		
<b>CATEGORY 1</b>	<b>CATEGORY 2</b>	<b>CATEGORY 3</b>
<b>The crises of living without</b>	<b>The crisis of living with</b>	<b>The crisis of living with illness and poverty</b>
Living without paid work Living without dignity Living without buying things the children desire Living without having money to pay for emergency medicines and treatment Living without meeting the social expectations Living without hope Living without being able to support the body Living without knowing Living without emotional support: the dilemma of disclosure	Living with stigma Living with preoccupation and constant worrying Living with other ill members in the family	Needs of the sick father versus needs of the child The need to rest versus the need to work Random (any) paid work versus selective paid work Voluntary work versus no work

**TABLE 2**

<b>THEME 2 : DISENGAGING FROM THE KNOWN : TOE KON EK NIE WEGKYK NIE — THEN I COULD NOT LOOK AWAY</b>			
<b>CATEGORY 1</b>	<b>CATEGORY 2</b>	<b>CATEGORY 3</b>	<b>CATEGORY 4</b>
<p>Choosing to know versus not knowing</p>	<p>Choosing to live versus choosing to die</p>	<p>Choosing to accept</p>	<p>Choosing to tell versus concealing</p>
<p>Choosing to know versus not knowing Making sure Seeking information and knowledge</p>	<p>Different reactions</p>	<p>Facing immediate fears</p>	<p>Dealing with a stigma trajectory</p>

**TABLE 3**

<b>THEME 3: ENGAGING WITH THE UNKNOWN : WHO WILL TAKE CARE?</b>	
<b>CATEGORY 1</b>	<b>CATEGORY 2</b>
<p><b>Facing the unknown</b></p> <p>Facing fears about dying: burdening the family versus being abandoned by them</p> <p>Facing fears about living: acceptance versus rejection</p> <p>Fears about being rejected by the community in which one lived</p> <p>Dealing with despair</p>	<p><b>Grappling with dichotomies</b></p> <p>Uncertain and limited time</p> <p>Honest work versus criminal activity</p> <p>Ambiguous community attitudes</p> <p>Ongoing contemplations about telling or concealing</p> <p>Fearing living without medical care</p>

**TABLE 4**

<b>THEME 4: RECONFIGURING FATHERING: I CAN STILL BE A FATHER</b>		
<b>CATEGORY 1</b>	<b>CATEGORY 2</b>	<b>CATEGORY 3</b>
<b>nothing really has changed</b>	<b>Everything has changed: <i>voorheen was ek – previously I was</i></b>	<b><i>I can still be a father</i></b>
<p>The father as sole breadwinner</p> <p>The father as a role model</p> <p>Fathers manage discipline</p> <p>The father nurtures his partner daily</p> <p>The father organizes the family routines</p> <p>The fathers dialogue with their partners on behalf of the children</p>	<p>Changes in personality</p> <p>Changes in the traditional provider role</p> <p>Employment for the ill</p> <p>Changes in type of occupation</p> <p>Changed attitudes in the workplace</p> <p>Making increasing life-threatening decisions</p> <p>Increasing the buffer zone between the family and the community</p> <p>Decreasing opportunities for engagement in paid and voluntary work in the community</p> <p>Appearing normal</p> <p>Restoration of energy levels by taking medication</p> <p>Improved family health practices</p> <p>Introducing health measures to prevent contagion within the family</p> <p>Increased family cohesion</p> <p>Renewed hope to be productive</p> <p>Renewed recognition of the value of engagement in occupation</p>	<p>Continuing fathering</p>

## CHAPTER 4: THE FINDINGS

University of Cape Town

## CHAPTER 4: THE FINDINGS

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In this section I will provide background information about the participants in order to contextualize the research findings. Thereafter, I will present the data analysis.

### 4.1 Background information

#### Participant A

A is a very proud and sensitive male of thirty years who lives in Retreat, with his partner aged twenty three years and their child. Although he is primarily Xhosa-speaking, he can express himself well in the English language. He is a polite and verbally succinct person who is motivated to achieve economic success and independence in order to provide for his family. He struggles to reconcile this need with his career ambitions for further learning and training, and the needs of his ill body. A does freelance photography at schools and this provides him with an irregular and insufficient income.

He lives in a rented room with his family. His partner does not work. Their main support system is A's parents. A is in stage 2 of the illness, and he had been on antiretroviral therapy for two years at the time of the interview. His partner commenced with antiretroviral therapy at the same Research Unit during the time of our interviews. His family did not know about his or his partner's HIV positive status.

### **Participant J**

J is a softly-spoken, thirty-five year old, proud Xhosa father. He lives in Philippi with his wife and two children aged two and six years. The family relocated to Cape Town from Beaufort West about one year ago, after he was retrenched and was unable to find alternative employment there. He has been unable to find employment as a meter reader in Cape Town, and has applied to the Small Business Development organization for financial assistance to develop a small home-based fruit, vegetable and grocery business. His wife is unemployed and the family has survived on his unemployment insurance monies that have since dried up.

He was diagnosed with HIV/AIDS in May 2000 (10 months prior to the interview) and was receiving counseling and tests at the Research Unit in preparation for commencing with the clinical trials. Although 'J' looked well physically, he was in stage 3 of the illness. His wife and one family member had been informed of his HIV positive status. J said that they spent a lot of time with their extended family who lived nearby.

### **Participant G**

G is a thirty-eight year old talkative and entertaining male, who lives in a shack in a settlement in Somerset West. His wife is twenty-six years old and they have two children aged two years and six years.

He is ambivalent about fathering and working because he is physically and emotionally frail. Despite this, he attempts to cope with the daily demands of his day. He felt sad about his reduced

and fluctuating capacity and his impoverished conditions of living. He receives a state disability grant (R630.00 per month February, 2002) because he is too frail to work in the open labour market and the family receives a child-care grant for the one child.

Previously J was a painter and a fisherman on ships based at Saldanha Bay and spent most of his time away from home. Since becoming ill with tuberculosis two years prior to the interview, he performed community work as representative of a local political group. Both his wife and younger child are HIV positive. Because his wife is also ill, he cares for the children and often needs to complete the housework too.

His eldest child was attending a crèche until J removed him because of the constant teasing about his sick family. According to the senior nursing sister at the Research Unit, G's family has rejected him since he disclosed his HIV positive status to them. G is in stage 2 of the illness and he had received anti-retroviral therapy for a seven-month period at the time of the interview. G's wife and younger child attend a Mother-to-Child Clinic for HIV positive mothers and infants and they receive anti-retroviral therapy too.

#### **4.2 The findings**

The following themes emerged from the analysis of the data.

**Theme 1: The crisis of living - *You got nothing really in your hand***

**Theme 2: Disengaging from the known- *Toe kon ek nie wegkyk nie: Then I could not ignore it***

**Theme 3: Engaging with the unknown: *Who will take care?***

**Theme 4: Re-configuring fathering – *Ek kan nog 'n pa wees: I can still be a father***

**Theme 5: Beyond fathering – *making a way***

Each theme is discussed in terms of its categories and sub-categories. The participant's quotes are presented in italics. Original Afrikaans quotes are followed by the English translation where applicable.

#### **4.2.1 THEME 1: THE CRISIS OF LIVING: *YOU GOT NOTHING REALLY IN YOUR HAND***

This theme describes what the conditions of living in poverty and with HIV/AIDS is like for fathers. The expression "***you got nothing really in your hand***" is to be taken literally because without a basic income they felt that the 'fathering hand' could offer the family nothing. Each day is characterized by an ongoing struggle for survival. This struggle is enduring and is aggravated by unemployment and the absence of financial alternatives that could fulfill their basic needs. The onset of illness augments the crisis of survival for them.

##### **4.2.1.1 The crisis of living without**

The participants shared all the things they needed but struggled to obtain because the family did not have an income to provide for their basic needs such as daily food, emergency healthcare and

emergency medicines. The struggle for survival for them is about living without having, without doing and without knowing.

### **Living without paid work**

This category describes the condition of living without resources needed for daily survival. Paid employment was the only viable source of income for participants but they were unable to obtain suitable employment. They felt that they were unable to continue fathering if they could not provide a basic income for the family. A said:

***“For as a father to live with HIV/AIDS is...is not good anymore ‘cause you struggle, specially if you don’t...if you don’t work and you both not working”***

The problem is compounded if the partner is also not working or unable to find work. When the partner is ill, the other partner needs to care for him/her and the family. The caring may include sick and well children.

G felt that it was necessary to have money to be a father and that without money he was unable to provide for his family.

He said:

***“Hoekom ek se dis baie hard uh...uh, ek kan nie werk vir my kinders nie...as jy werk dan kyk jy jou familie...kyk...dis hoekom as jy werk het jy geld, as jy nie geld het nie kan jy nie na hulle kyk nie”***

***“Why I say it’s very hard uh...uh, I can’t work for my children...if you work then you can look after your family...see...that’s why if you work you have money, if you don’t have money then you can’t look after your family”***

### **Living without dignity**

Because the fathers were unable to provide for their family's basic needs, they felt deprived of their dignity and this contributed to feelings of despair, shame and alienation within the community. A said:

***“You tell yourself...I look like nothing on this world...you rather maybe die”***

### **Living without buying things the children desired**

G expressed his sadness because he was unable to buy the things his children desired. He said:

***“...Ek kan nie uh goeters koop wat my kinders begeer nie”***

***“ I can't buy my children the things they desire”***

### **Living without having money to pay for emergency medicines and treatment**

Living without a basic income also meant that a father was unable to save his child from life-threatening situations because he was unable to afford the required health services and medicines. The father needed money for transport fares and to purchase medicines.

***“The child, if maybe he/she don't got treatment...yes, maybe can loose your child because you don't know where to go especially if you are not employed, yes...”***

A serious consequence of non-treatment was that children could die. A's youngest child suffered from epilepsy in addition to being HIV positive. He had already contracted a number of opportunistic infections. Two of the participants related how the children frequently became ill during the night. In these situations they did not have the necessary medicines for the children nor did they have money for transport fares to an emergency hospital.

### **Living without meeting the social expectations**

By being unable to provide for their family's needs they felt unable to meet the family's and the community's occupational expectations of a father. G described this feeling of exclusion and alienation.

***“Dit laat my, dit laat my, dit laat my so uit die gemeenskap uit voel...uh, ek het niks...die ander het iets”***

***“It makes me, it makes me, it makes me feel out of the community...uh, I have nothing...the others have something”***

Poverty and illness became interlinked – the fathers had no resources on which to draw and now they were unable to work because suitable work was not available for them.

### **Living without hope**

The double impact of the illness and living in poverty was demoralizing for the fathers. A said:

***“...Because sometimes you loose faith, you loose hope, when you are in this problem”***

It was as if there is no way out for them when they ***“...are in this problem”***

### **Living without being able to support the body**

Health professionals educate persons with HIV/AIDS to eat healthily. However, the participants were unable to promote their health (within the HIV/AIDS experience) by eating healthily because they did not have the finances to do this.

***“You don’t have money to buy healthy food...you try to get things you can also support your body”***

### **Living without knowing**

The fathers felt that they did not have the necessary information to be able to utilize resources, services and facilities. Because they were unable to be self-sufficient, they required external assistance to be able to survive. Accessing this meant having critical information available to them. For example, A did not know where to obtain social assistance. He felt additionally stressed because this critical information was unavailable to him. He said:

***“Then also affect you because you stress a lot because you don’t know whereto can you help yourself...where to go and have help”***

## **Living without emotional support: the dilemma of disclosure**

Participants were hesitant about disclosing their HIV positive status to partners, family and friends because they feared being rejected. However, both disclosure and non-disclosure could cause them to lose the support and care that they required. A said:

***“What your...really problem is...is difficult to speak out”***

A feared losing the family's support completely.

***“Sometimes you tell them (the family) because you trust them and then after that they ignore you, they don't even want you to stay to be part of the family, let to be together in their house, they just want to chase you away, make your own way you see, they don't want to come and comfort you”***

Thus without having money and paid work and without critical information to access resources to be able to provide for the family, the participants felt that it was difficult to continue fathering. They also felt ashamed about not being a breadwinner in a community where the father is expected to be a provider.

### **4.2.1.2 The crisis of living with**

In this category the participants describe what the double crisis of living in poverty and living with HIV/AIDS illness is like for them. While striving to survive, they are required to deal with societal attitudes of stigmatization and discrimination against persons with HIV/AIDS. These negative attitudes precluded them having free and equal access to resources that are available to persons without illnesses and persons who are not poor.

### Living with stigma

The participants experienced being blamed for their illness and ostracized because family and community members feared becoming infected if they were in contact with an infected person. A explained:

***“They think maybe you choose to be but they don’t know maybe where did you get affected”***

G described how the community had labeled his family because three out of four members were infected. Being identified as *“the sick family”* was experienced by the family as being regarded as a family that infects others. The community therefore felt very threatened by the illness. By identifying them as the ill family, the community was sending a clear message to everyone that the illness was contagious. This meant that they needed to avoid being in contact with the sick family. G explained:

***“Hulle ken al vir ons, bekend in die gemeenskap..dies die .....die is nou die siek familie”***

***“They recognize us, well-known in the community...the .....this is the sick family”***

### Living with preoccupation and constant worrying

The inner resources are challenged to manage a preoccupation with the illness and the heightened uncertainty of living and surviving. J described this feeling as:

***“...jy dink dat jy’s HIV positief...dit bly in jou gedagte”***

***“..you think about being HIV positive...it stays in you thoughts”***

Another aspect of the preoccupation concerned the family. He said:

***“As ouer dink jy aan jou kinders en jy dink aan jou vrou, as jy miskien moet sterwe en wat gaan gebeur met hulle”***

***“As parent you think about your children and you think about your wife, and what will become of them if you die”***

#### **Living with other ill members in the family**

The participants described how living was further complicated when other family members were infected.

***“Yes we did struggle long, a lot, because we had the child and then also this child is leading the same situation”***

#### **4.2.1.3 The conflicting struggle of survival and illness**

The participants expressed that survival and development needs conflicted with their illness needs. It was difficult and frustrating for them to balance the role of the well father and the role of the ill father and this resulted in role conflict.

#### **Needs of the sick father versus needs of the child**

Being angry conflicted with being a good and loving father especially if the child was ill. This was stressful for the sick father because his role is to reprimand and guide the child. G described this feeling of conflict:

***“Um, om pa te wees is baie hard vir my om pa te is, want die kinder wat HIV het, en in my huis is daar baie vol stress; jy raak gou kwaad, jy het ‘n kind in die huis en die kind vang iets aan wat nie reg is nie dan...dan dit weerkaats by jou siekte, um...jy moet liefde in ‘n huis..”***

***“Um, to be a father is very difficult for me because you have a child with HIV and this makes the home full of stress; you get angry quickly when the child does something wrong...this conflicts with your illness, um...there must be love in the home”***

#### **The need to rest versus the need to work**

The participants experienced a conflict between the need to rest the ill body and the energy required to perform paid work. A said: ***“Your body also need to rest...to rest where you...you...you got you receive more energy you see. Rest your mind, rest your body...you see, because you got no energy to go on with your work you see”***

#### **Random (any) paid work versus selective paid work**

All the participants were prepared to perform any paid work. However, A and G spoke about a growing realization that their illness required them to be selective about their choice of work.

### **Voluntary work versus no work**

G desired to work outside his home even though it would be unpaid work. He referred to this as voluntary-community work. However, access to this type of work was denied to him by community leaders who considered him to be too frail and ill to work. This conflicted with his desire to be occupied outside the home and to perform recognized community work.

***“Die gemeenskap wil nie meer he ek moet werk daar nie, maar ek voel ek kan nog werk in die gemeenskap en ek kan iets doen...dit laat my meer gelukkig voel, as ek so sit, dit lat my siek voel en siek raak”***

***“The community do not want me to work there, but I feel I can still work and I can do something...this makes me feel happier, instead of sitting, it makes me feel sick and I become sicker”***

#### **4.2.2 THEME 2: DISENGAGING FROM THE KNOWN: TOE KON EK NIE WEGKYK NIE-THEN I COULD NOT LOOK AWAY**

Here the fathers describe their initial reactions to finding out about their HIV positive status. Although their initial reactions were to deny the diagnosis, they resisted this and started looking towards confronting the impact of the diagnosis on their lives and their family's lives. They discussed their strategies for coping with the devastating diagnosis. They described the dilemma of opposing internal forces and how this coerced them into making decisions between life and death.

#### **4.2.2.1 Choosing to know versus not knowing**

Frequently, a positive diagnosis was made after a routine medical examination for an enduring medical complaint. The participants felt unprepared to deal with the impact of the diagnosis. Denial and escape options were considered initially by two of the participants while the third participant withdrew and became preoccupied. J needed time to be alone. He said:

***“Daars somtyds tye wat jy alleen wil wees en...en...en dan dink jy aan dit, ja”***

***“There are times when you want to be alone and...and...and then you think about it, yes”***

#### **Making sure**

In this category the participants made an intentional shift towards acknowledging their HIV/AIDS status. Two participants asked to be retested immediately.

***“Ek kon dit nie vat nie...ek...ek het gese dokter is verkeerd, U moet weer bloed trek en dit oordoen...en hy het gese ek gaan nie stry met jou nie, ons doen dit maar weer 'n keer en regtig...toe hy nou weer dit doen, kon ek nie wegkyk nie”***

***“I could not cope with it...I...I told the doctor he is making a mistake, he must draw blood again and retest me...and he said he was not going to argue with me, that he would retest my blood and really...after he retested it, I could no longer deny it”***

### **Seeking information and knowledge**

Having accepted the initial diagnosis, the participants sought information about the illness. One participant was fortunate to have access to a counselor for post-diagnostic counseling. J explained:

***“...Ek kon dit nie eens aanvaar nie, ek het vrae gehad, wat gaan ek nou doen en wat gaan met my gebeur en...maar ek het ‘n counselor gekry en ek het dit aanvaar...”***

***“I could not accept it initially, I had questions, what am I going to do now and what will happen to me and...but I spoke to a counselor and I accepted it...”***

Two participants were anxious about how debilitated they would become in the terminal stage of the illness and desired to see what they would look like physically. A said:

***“I went out and go and do some research to get more information, what is this you see, and then also my feeling I want to see the person...the person who is HIV positive or the person who is already got AIDS you see, ja”***

#### **4.2.2.2 Choosing to live versus choosing to die**

The participants described different reactions to having their HIV positive status confirmed medically. Two participant's considered suicide immediately after the diagnosis was confirmed but decided to live with the illness instead. The third participant considered committing family suicide when he continued to struggle for acceptance within his community. A explained:

***“I went to the doctor and then he told me hey this is the results about you...I get shock...I felt I can go home and kill myself...but I didn’t do that”***

#### **4.2.2.3 Choosing to accept**

After choosing to live rather than die, the fathers decided to accept their illness tentatively and to deal with some of the immediate fears. One fear was the fear of potential partner desertion and another fear was the fear of partners being infected or becoming infected. In one instance, the participant received vicarious acceptance after his partner tested HIV-positive. This prevented a marital separation.

***“Toe ek siek gewees het...die dokter praat met haar, ek is siek ek het HIV, dat ek nie genees raak nie, toe’t sy baie...sy was nie saam met my nie...sy wou my gelos het...nou is ons gelukkig, ons altwee is nou siek”***

***“When I was ill...the doctor spoke to her, told her I am sick with HIV, that I can’t be cured, then she...she did not support me...she wanted to desert me...now we are happy, we are both ill”***

#### **4.2.2.4 Choosing to tell versus concealing**

This involved taking personal-emotional risks because society at large discriminated against persons with HIV/AIDS. Choosing to tell is an attempt by the participants to include significant others into their new experience and to promote their acceptance and support. This is done at the cost of potentially experiencing rejection and discrimination.

## Dealing with a stigma trajectory

The decision to disclose one's HIV positive status is difficult to make because of the fears and prejudices surrounding the illness, within the immediate and broader society. Disclosure is also not a once-off experience but is managed differently within the different stages of the illness. The work of "telling" became one participant's real work. Disclosing is managed carefully and selectively to reduce the high risks of rejection. Therefore, two participants disclosed to partners initially while the third participant disclosed to a supportive family member. These persons were approached sensitively. J explained the sensitive approach:

***"Wanneer jy die probleem dat...jy raak bekommered, hoe gaan jy gehanteer word en uh hoe gaan die persoon dit ook aanvaar, en dis dinge wat jy rerig, you must be sensitive en uh, dis wat ek gedoen het"***

***"When you have this problem...you become worried, how are you going to be handled and uh, how will the person accept it, and these are the concerns, you must be sensitive and uh, that's what I did"***

However, not telling also presented a personal threat.

***"As ek nie dit vir my vrinne vertel nie, dan ander woorde ek um ek...ek gaan later vir my wegsteek because ek is bang, hulle gaan uitvind ek het die siek"***

***"If I don't tell my friends, in other words I um I...I'm going to hide away because I am afraid that they will discover that I have the illness"***

For J, being discovered was equated with being rejected. To compensate for this he adopted the approach of telling everyone about his HIV positive status. This fitted with his life ideal of indiscriminate honesty and openness at all costs. At the time of the interview, the participants were staged essentially in the asymptomatic stage of the illness and their illness was largely invisible. This promoted the opportunity to engage support while their physical condition was largely invisible and the illness was not apparent.

#### **4.2.3THEME 3: ENGAGING WITH THE UNKNOWN: *WHO WILL TAKE CARE?***

The fathers explored future concerns and options available to them within the new experience of the illness. They experienced many concerns.

##### **4.2.3.1 Facing the unknown**

This category alludes to the inner fears the participants described about their future. It contained simultaneous fears about living and surviving as well as fears about dying. The fathers feared both the uncertainty and the certainty of dying. They feared dying because they were uncertain about how their families would cope without them. J explained:

***“Jy sit bekommerd want jy weet nie wat gaan more...wat gaan gebeur nie en wat gaan gebeur met jou familie”***

***“You are worried because you do not know what tomorrow...what will happen and what will happen to your family”***

### **Facing fears about dying: burdening the family versus being abandoned by them**

The participants hoped not to become a burden to the family when they became bedridden in the final stage of the illness but did not want to be abandoned by them either. They felt ambivalent about needing to be cared for and about caring for their families. They also felt ambiguous about the families and friends' loyalty towards persons that experienced a lengthy illness. They were unsure whether their loyalty would endure for the duration of their illness. One participant had experienced neglect from his family and friends while he was hospitalized for the treatment of his tuberculosis. This experience made him doubt whether his family and friends would continue to care for him.

### **Facing fears about living: acceptance versus rejection**

The fathers feared living without the acceptance of their families and communities. J explained:

***“Want ek het al gesien uh...mense wat weggestoot word van hulle familie as hulle HIV positief is”***

***“Because I have seen uh...people that get rejected by their family when they are HIV positive”***

### **Fears about being rejected by the community in which one lived**

The community in which one participant lived, had expressed their fears of contagion towards G and his family and this reaction had prompted him to consider leaving the community.

***“Ek het al gevoel dat ek uit die gemeenskap uit gaan because by hulle hoor ek van ‘julle het HIV, julle gaan ons aansteek’ ”***

***“I felt like leaving the community because I heard them saying ‘you and your family have HIV, you are going to infect us’ ”***

This experience was not the same for the other participants because their communities did not know about their HIV positive status. So they continued to receive the same level of care from them. They chose not to tell persons in their communities because they feared becoming rejected by them.

### **Dealing with despair**

The ongoing struggle for care and acceptance also precipitated thoughts about family suicide.

***“As ‘n pa het ek net gevoel ek sal nie langer met die pyne nie en die pyne is baie swaar vir my, toe het ek maar besluit ek gaan maar ons familie almal self doodmaak”***

***“As a father I felt that I was unable to endure the pain for longer and the pain is very difficult for me, so I decided to kill my own family myself”***

#### **4.2.3.2 Grappling with dichotomies**

The fathers experienced many fears about living with the illness. These fears conflicted with each other.

##### **Uncertain and limited time**

Time became limited but also uncertain and influenced the father's choices about their future's and the futures of their families. A was required to make instrumental decisions about opting for career training or opting for paid work. He explained:

***“And then I even got the opportunity, the chances to do the studies...maybe I'm gonna study for more than three years and then I work for two years and then.....This rather maybe try to go and find employment...try to see how I can help myself you see”***

Because A's illness was terminal, he chose to be a good father by getting a paid work and providing for his family instead of developing a career path for himself. J also realized that his time was limited. This motivated him to use the given but uncertain time limit to achieve his goals of his fathering and his life. The uncertainty of time for the participants' lives thus coerced them into reflecting occupations. This enabled them to prioritize options.

##### **Honest work versus criminal activity**

For the participants there were only two options to support their families – honest work or engaging in criminal activities. This work

alternative became a serious consideration because work was scarce and being accepted for work when you had HIV/AIDS was difficult. A said:

***“Sometimes you think okay, what can I do now...you see some other people...rob you see because they want to help themselves’***

### **Ambiguous community attitudes**

The community tended to overprotect an ill person from performing voluntary work. This conflicted with the participant's need for meaningful occupation. This was true for the one participant because the community was aware of his physical frailty. J explained:

***“Ek vra hulle (gemeenskap) alles, dan se hulle nee ek kan nie so baie werk nie ek is siek, dan se ek nee mm...dit maak my nog luier as ek so sit, ek wil iets doen dat ek net kan besig is”***

***“I ask them (community) for work, then they say no, I can't work because I am sick, then I say no mm...I become even lazier when I just sit and do nothing. I want to do something so that I can just be busy”***

### **Ongoing contemplations about telling or concealing**

Family support and support from friends was a vital resource for continuing fathering, yet this was uncertain in all instances and disclosure was therefore managed very selectively and in some cases not a viable option. These considerations were ongoing

and were weighed up against the risks to the father and his family if he disclosed his HIV positive status.

***“No at the moment...I didn't tell my family...ja I didn't told my family. Even I don't want somebody to go and tell my family now, I just want to keep it personally...because also I'm scared maybe they can ignore me you see”***

The fathers' careful deliberations brought them to a realization that the conditions for living have changed. In order to continue, they required the ongoing acceptance and support of their partners, immediate family and the community.

#### **Fearing living without medical care**

The fathers feared the struggle of living with illness and being unable to afford essential medical care for themselves and their children. A said:

***“Yes we did struggle ...a lot because we had the child and then also this child is leading the same situation and then sometime the child is get flu, sometime the child just get special sickness you see and we have to take him to doctors...go...sometimes sleep in the hospital because of the child. The child if maybe he/she don't got many treatment...maybe can loose your child”***

All these fears and uncertainties about living and dying caused the fathers to feel unsure about the future. J said:

***“Jy sit bekommerd want jy weet nie wat gaan more...wat gaan gebeur nie en wat gaan gebeur met jou familie”***

***“You are worried because you do not know what tomorrow...what will happen and what will happen to your family”***

#### **4.2.4 THEME 4: RECONFIGURING FATHERING: I CAN STILL BE A FATHER**

The fathers struggled to understand a complex duality: could they still be fathers when they were unable to be the breadwinner and were going to die? Or if they continued their routine fathering occupations, could they still be fathers to their children? The latter perception implied that nothing had really changed for them. The participants shared how they applied cognitive appraisals on a subconscious level to establish that their fathering occupations had remained the same. This refers to the fact that they had made occupational adaptations on a sub-conscious level and were therefore unaware of having done so. On a conscious level they were able to gauge that their fathering had remained unchanged. Therefore, J concluded:

***“Ons is maar nogsteeds dieselfde, ons doen dieselfde dinge wat ons gedoen het en daar het niks verander regtig nie”***

***“We are still the same, we do the same things that we did and nothing really has changed”***

This finding may also indicate that the fathers perceived their primary role to be unchanged or independent of what they did or did not do.

#### **4.2.4.1 “nothing really has changed”**

Here the fathers described the fathering occupations that have remained the same for them.

##### **The father as sole breadwinner**

The participants regarded provider occupations as the primary occupation of fathers. So their main focus remained on planning ways to obtain finances to provide for the families' basic daily needs.

##### **The father as a role model**

In addition the father set an example for the children to follow:

***“Jy moet werk vir jou kinders om ‘n voorbeeld vir hulle te het as hulle groot is, dan moet hulle werk...om te lewe”***

***“You must work in order to be a role model for your children so that when they are adults, they also work...in order to survive”***

This finding also implies that ‘poverty-related behaviors’ may be learned. J set an example by loving his children and ensuring their happiness. The participants regarded fathers as heads of households who needed to set health examples for the family.

***“Ek is die vader in die huis. Omdat ons almal siek is, moet ek eerste die pille drink dan moet hulle ook drink. As ek dit nie gaan doen nie, gaan hulle dit ook nie drink nie’***

***"I am the father of the home. Because we are all ill, I must drink the medicine first, then they must also drink it. If I don't do it, then they will also not drink it"***

The enduring patriarchal influence is evident here:

#### **Fathers manage discipline**

Fathers were to be relied on for dealing with problems and for disciplining the children. For J, this fathering occupation was regarded as unique to the father. He stated:

***"Daar kom tye waar hulle...die kind rerig dik stem wil hoor...wanneer..sy miskien verkeerd stap. Kyk die moeder is daar...sy sal maar net praat en dan...Wanneer die pa stem dik gemaak het, staan sy terug en...sy...doen dit moes nie, want die pa sal mos bietjie skrikkerig wees"***

***"There are times when they...the child really needs a stern voice...when she has done something wrong. Look the mother is there...but she will just talk and ...When the father talks sternly, she stands back and...she...does not do it again, because she is a little afraid of the father"***

#### **The father nurtures his partner daily**

Another participant described the father's nurturing occupations towards his partner to include listening to her at the end of a day.

A said:

***“You must also ask what is their day (um)...so that you know that maybe your partner doesn’t stress”***

### **The father organizes the family routines**

The participants explained that the father organized and regulated the daily and weekly routine of the family. Religious activities formed part of the weekly evening routine for J. The fathers collaborated with their partners around these routines.

### **The fathers dialogue with their partners on behalf of the children**

The participants discussed the need for them to dialogue with their partners on behalf of the children sometimes as another necessary fathering occupation. Negotiating involved persuading the partner to give in to something the children wanted to do.

***“...daar is tye wat sy nou voel sy wil nou nie gaan nie, maar dan kom die kinders en hulle verlang miskien nou die ouma...Daddy praat met mammie dat ons ‘n bietjie loop kuier by ouma”***

***“...there are times that she feels that she doesn’t want to go out, but then the children come and they wish to visit grandmom...Daddy speaks with mommy about visiting grandmom “***

#### **4.2.4.2 Everything has changed: voorheen was ek...: previously I was...**

Here the fathers described how fathering was different from the father's ideal and how it had changed since the onset of the illness. The fathers described the adaptations they had made in relation to their fathering ideal and their illness. At the same time they were unaware of having made these adaptations that enabled them to continue their fathering occupations. Thus they said that *“nothing has really changed”* while simultaneously describing that **everything had changed**. There were positive and negative changes.

#### **Changes in personality**

G described experiencing changes in his mood and personality. He said:

*“Uh voorheen was ek, ek was gewillig om iets te doen, ek was baie praterig, spelerig en nou is ek nie meer so nie”*

*“Uh previously I was eager to do things, I was talkative, playful and now I am different”*

#### **Changes in the traditional provider role**

The participants experienced most changes in relation to their provider occupation. It was difficult to accept decreasing physical capacity for formal work and this resulted in a negative self-image. One father described this experience as follows:

***“Ek was ‘n gesonde man gewees, hardwerkende man...soos ek nou is, is ek nie meer so nie...ek kan nie werk nie en dit laat my sleg voel...sleg...sleg”***

***“I was a healthy man, a hardworking man...but I am no longer...I cannot work and this makes me feel bad...bad...bad”***

G was ambiguous about his ability to work and his need to work. The other fathers struggled to reconcile the necessity and social expectation for providing for their families and the unavailability of formal work or other financial alternatives.

### **Employment for the ill**

The fathers were required to be selective about the work they performed in order to match their fluctuating and decreased capacity for work in the open labour market. They required regular periods for resting and therefore needed to pace their work carefully to enable them to continue working.

### **Changes in type of occupation**

Although stage 2 of the illness is an asymptomatic stage, the fathers experienced a reduction in their energy levels as well as fluctuating energy levels. Thus their work capacity had changed and they required less demanding work or strategies for doing their work differently so as to conserve their energy. This included having regular rest periods because their endurance was lower. A formal workplace did not provide this flexibility in method of work or work routine. G discovered that his energy levels were

best suited to 'soft work' as opposed to manual work that he had performed prior to his illness.

### **Changed attitudes in the workplace**

When applying for new work, participants experienced direct discrimination as a result of fears of contagion in the workplace.

J explained:

***“As hy kom uitvind, dan gat hy se jong, ek het nie meer werk vir jou nie. Dit het al gebeur met my... omdat ek is... omdat hy weet ek het HIV en hy is bang ons gat ook vir hom aansteek”***

***“If he finds out, then he will say um, I don't have any work for you. This has happened to me... because I am... because he knew that I have HIV and he is afraid that we will infect him”***

Despite all these work-related difficulties, the participants still regarded themselves as the primary breadwinner of the family. It was as if proof of good fathering was only acknowledged through this provider role. So they continued to hold themselves responsible for the financial welfare of their families, regardless of whether this was obtained independently or through social assistance. For example for G, this provider role included arranging for social assistance and managing the family budget.

### **Making increasing life-threatening decisions**

Fathers living with a partner with HIV/AIDS are also faced with increasing life-threatening decisions. J, in order to save his child's life decided that the infant had to be breastfed by his HIV positive mother because the infant refused to accept alternative feeding.

The infant subsequently developed HIV. J described how this life-threatening decision made him feel:

***“Dit was ‘n swaar besluit...toe’t ek net besluit nee man om daai dinge, lat die kind maar aan die ma drink, maybe sal die Vader besluit die kind gaan nie siek nie”***

***“It was a difficult decision...then I decided no man for those reasons, let the child drink from the mother, maybe the Father will decide that the child will not become ill”***

However, in the absence of available medication at the time of the infant’s birth, this infant did become infected with the HIV virus. (The anti-retroviral, Nevirapine, advocated for the prevention of mother-to-child transmission, was approved by the High Court in a counter-hearing in Pretoria on 11 March, 2002. However, this ruling is being challenged by the South African Government).

### **Increasing the buffer zone between the family and the community**

Within the family living with HIV/AIDS, the father assumed a more active protective role within the community. In one instance, J decided to remove his child from a school that did not control and prevent direct teasing and discrimination about the father’s HIV positive status. This is his account:

***“Uh, jou pa is siek en sulke goeters, ...ek gaan nie lat my kind aanhou die dinge hoor nie...dis hoekom ek my kind gestop het by die creche, hy moet maar by die huis bly”***

***“Uh, your father is sick and things like that...I’m not going to allow my child to continue hearing these things...that is why***

***I stopped him from going to the crèche, now he must stay at home”***

Thus the father responded by overprotecting the child and the family from the negative attitudes and behaviours experienced within the community. This response however, would serve to isolate the family more within the community and deprive his child of the right to education.

### **Decreasing opportunities for engagement in paid and voluntary work in the community**

J experienced direct exclusion within the community that prevented him from engaging in paid and voluntary work occupations. This was the result of stigmatization and the labeling of his family as “*the sick family*”. This created a negative perception of the participant and his family as being infectious and lazy. In this way the family became more alienated within the community.

### **Appearing normal**

In order to be allowed to participate within such a discriminatory community, the fathers were expected to maintain an appearance of normality by denying the true experience of their illness.

***“Ja dis pynlik, ek lewe...ek is al gewoond aan die pyn...ek kla nie meer nie...en loop nie inmekaar nie, wys vir ander mense, dis why ek is soos ‘n gewone persoon, ek is al gewoond aan die pyne”***

***“Yes, my life is painful...I am used to the pain...I don't complain any longer...and don't walk around, showing other people, that's why I am like a normal person, I am used to the pain”***

### **Restoration of energy levels by taking medication**

The fathers' activity levels improved when they used anti-retroviral drugs. This was perceived as a positive change.

J explained:

***“Sodra ek die pille in my het...dan voel ek weer lus vir lewe...ek werk by die huis en ek loop vee...vee by die huis, ek werk in die garden ek...ek doen 'n bietjie community werk in die gemeenskap”***

***“When I take the medicine...then I feel enthusiastic about life...I work at home and I sweep...sweep the home. I work in the garden I...I do a little community work in the community”***

### **Improved family health practices**

The family health practices become directed to “*support the body*”. This became a core motivation for A for gaining paid work because it cost money to buy healthy foods to sustain his and the family's health.

J became more aware of his responsibility to ensure standards of basic family hygiene. He said:

***“Vir my as vader is dit...is dit my plig om te kyk vir gesondheid in die huis. Gesondheid in die huis is goeie kos...skoon klere, gesonde kos eet”***

***“For me as a father...it is my responsibility to care for the health in the home. Health in the home is good food...clean clothes, eating healthy food”***

### **Introducing health measures to prevent contagion within the family**

As a result of multiple-infections within one family, the father introduced a separate health routine for those members who were infected and those who were not infected. For example, the infected members shared foods from the same plate and drank from the same mug, while the member who was not infected was required to use separate crockery.

***“Die ene wat nou nie siek is nie, ek is baie versigtig dat hy nie saam met ons moet eet uit een bord uit nie, maar ons wat nou siek is, die drie in die huis ons eet saam ons d...drink saam water”***

***“The one that is not sick, I am very careful that he doesn't eat from the same plate, but we three who are ill, we three eat together we d...drink water together”***

### **Increased family cohesion**

The fathers experienced real and vicarious increases in family cohesion as a result of their illness. For example, G's family was closer since other family members were also ill. Family support contributed positively to real support. J said:

***“Ja, ek is nou baie geheg...ja nou is ek baie geheg aan die familie en so aan omdat hulle ook 100% langs my staan...Dit maak ook dat jy positief lewe”***

***“Yes, I am very attached...yes now I am very attached to my family and so because they support me 100%...This makes me live positively”***

### **Renewed hope to be productive**

By continuing with their fathering occupations, the participants recognized that they could still be active and productive. J exclaimed:

***“Ja, daar is nog baie dinge wat ek kan doen”***

***“Yes, there are still many things I can do”***

### **Renewed recognition of the value of engagement in occupation**

Although the fathers lived with illness, they were aware of the psychological value of engagement in occupation for themselves. J claimed:

***“Maar ek voel ek kan nog werk in die gemeenskap en ek kan iets doen...dit laat my weer gelukkig voel, as ek so sit, lat my siek voel en siek raak”***

***“But I feel I can still work in the community and do things...this makes me feel happy, rather than sitting, this makes me feel sick and I become sick”***

This finding has important implications for the value of occupation for persons with illnesses.

#### **4.2.4.3 I can still be a father**

After configuring the major changes that have taken place in their lives, the fathers reach a point of realization or awareness that they can continue to be fathers. J expressed this awareness.

***“Dit voel vir my as ek...dit voel vir my ek voel groot en ek voel gesond en ek kan nog iets doen. Ja ek kan nog pa wees ja”***

***“It feels to me as if...it feels to me, I feel important and I feel well and I can still do things. Yes I can still be a father”***

#### **4.2.5 THEME 5: BEYOND FATHERING: MAKING A WAY**

Emerging within the previous theme and the final theme is the recognition of an extended identity that goes beyond living as father with HIV/AIDS, to a person living as a human and occupational being. The person is characterized by vulnerabilities and needs. This implies a shift away from the father as omnipotent and the sole provider, to a person who lives interdependently. Thus the fathers described their active ways of living with the illness and propose ways for others to assist them to live with the illness.

##### **4.2.5.1 The things I can do**

Here the fathers describe the things they can do that enable them to live with the illness.

### Fostering self-acceptance: I never know

A explained that his ignorance and lack of education about HIV/AIDS had contributed to his HIV positive status.

*"They (the family) think maybe you choose to be but they don't know maybe where did you get affected you see, because as I grow up I never heard what is AIDS, what is HIV, how you get affected with the HIV this disease, I never know"*

### Fostering an acceptable understanding of the illness for oneself

J fostered his self-acceptance and self-understanding by separating HIV and AIDS into an *"inner"* and *"outer"* illnesses. He explained:

*"Die HIV is 'n innerlike siek...is 'n pynlike iets...jy kan sien die persoon het AIDS, dis aansteeklik dis why dis 'n uiterlike pyn voel, jy kry sere en dit wys uit jy het AIDS...HIV jy kan nog nie sien nie...dis 'n binnerlike iets, pynlike iets, jy lyk gesond maar jy siek binne in, ja"*

*"This HIV is an inner illness...it's a painful thing...you can see a person who has AIDS, it's infectious and that is why it's an outer pain feeling, you get sores and it shows that you have AIDS...HIV you cannot see...it's an inner thing, painful thing, you look well but you are ill inside, yes"*

The inner illness is perceived to be an invisible inner pain while the outer illness is perceived to be contagious because it is visible. By separating the illness in this manner, G rationalized about the safety and acceptability of his illness. Thus he believed that he could not infect others. Society is generally

more tolerant and sympathetic towards persons with non-visible and non-infectious diseases. By assuming this view of his illness, G fostered a self-acceptance and attempted to elicit acceptance for himself and his family within his community.

### Fostering normality

The fathers participated in everyday occupations in order to feel like an *“ordinary person”*. An ordinary person was perceived to be pain-free, active and productive. Such a person was also acceptable to society. J explained:

*“Hy’t so gemaak om...om nie vol pyne te wees nie, om dinge te vergeet, om soos ‘n gewone mens te voel”*

*“He did that to...to rid himself of pain, to forget his pain, in order to feel like an ordinary person”*

### Participating in anti-retroviral therapy

The fathers realized that their longevity and feeling of well-being (and normality) could be extended when they used anti-retroviral drugs.

*“Dit bedoel...ek bedoel daarby as ek nie my pille drink en goed eet nie en na my kyk nie, dan gaan ek gou sterwe...die pille hou vir my nog aan die lewe, bou my body op en...die pille lat ek reg voel, ek kry nie pyne nie”*

*“This means...what it means is that if I drink my pills and eat healthily and take care of myself, then I won’t die soon...the pills keep me alive, make me strong and...the pills make me feel well, I don’t have pain”*

For G the experience of pain was equated with something foreign and abnormal. He experienced fluctuating pain throughout his body continuously, although he did have some relief when he was taking anti-retroviral drugs. G was more physically and psychologically frail than the other fathers.

### Sharing medicine-taking routines

G described experiencing increased family cohesion when the family shared their medicine-taking routine. This was pertinent to his family only because the experience of common illness had drawn his family together. In contrast, the other families had other means of experiencing togetherness such as going out together.

### Continuing with hobbies

There was the recognition of the importance of everyday, relaxing occupations for de-stressing and distracting one's preoccupation with the illness. A explained:

*"If you...you like music...playing music as usually...don't change your hobbies...if you like to play soccer go and play soccer, talk to people you see, don't focus that I'm HIV and I'm gonna die...is the way how to get your rest, you see"*

### Talking to others

The fathers all emphasized how **"talking to others"** was a necessary occupation to decrease their preoccupation with the illness and to reduce their feelings of isolation. J said:

***“Dan voel jy rerig beter...omdat jy nou gesels het...jy...jy sit nie met die ding binne in jou nie en so ek glo dat die ‘sitting with this thing’...om vir jou aan die gang te kry is dat jy moet gesels en se hoe jy voel...dit met jou familie , ja”***

***“Then you really feel better...because you have talked...you...you do not sit with this thing inside of you and so I believe that sitting with this thing’...to help you recover you must talk and say how you feel...with your family, yes”***

Talking with supportive family and friends promoted feelings of acceptance and this was important for the father. J explained:  
***“As ek met mense praat dan ek...ek kry lus vir die lewe...jy voel gesond en jy voel gelukkig ook omdat mense aanvaar jou so en jy...jy voel better”***

***“When I talk with people then I...I feel eager to live...you feel well and you feel happy also because people accept you and so you...you feel better”***

### **Creating new working occupations**

J created a new community work for himself by spending much time with community members to provide them with information about HIV/AIDS, to correct their misperceptions and allay their fears of contagion. He spent time engaging leaders in the community to support him when he experienced negative reactions to his illness. He referred to this spiritual work as:  
***“Ek bring die lig vir hulle”***

***“I bring the light to them”***

### **Adjusting the fatherhood ideal**

The fathers spent time adjusting their fatherhood ideal to fit the circumstances of their illness. The fatherhood ideal became adjusted when the fathers realized that they were unable to work in the formal sector because of their fluctuating work ability and negative employer attitudes. Through this they discovered they could still be fathers. J said;

***“Ek glo dat ek kan nogsteeds my familie gelukkig maak en gelukkig hou terwyl ek nog krag het”***

***“I believe that I can still make my family happy and keep them happy as long as I have the strength”***

### **Discovering new fathering occupations**

J discovered a number of new fathering occupations through his increased involvement with his family. He also learned to perform additional household tasks to compensate for his partner's decreased ability as a result of her illness condition. He learned to differentiate between the needs of the infected and the un-infected child: the infected child required critical caring while the un-infected child required developmental caring. He claimed:

***“En ek het..self die experience opgedoen dat die pa is ook nodig om aan die kind te kyk”***

***“And I...learned by myself that a father is also necessary to care for the child”***

### Career planning

The fathers re-engaged in planning their careers in order to support their families once they had familiarized themselves with the conditions for living with HIV/AIDS.

A continued his freelancing photography while training at a driving school to obtain his license to become a taxi-driver. J planned his future work around his home base. He had applied for a small business loan to initiate a fruit and vegetable store at his home.

He said:

***“Ons beoog om sommer dit voor die yard daar stand te maak verkoop en so aan...dit voel goed want ek glo dat uh as ‘n pa wil jy graag sien jou kinders is hier rondom jou”***

***“We plan just to in the front yard, place the stand and so on...it feels good because I believe that a father enjoys having his children around him”***

#### 4.2.5.2 The things others can do to make a way

The participants described the responsibility of the community in facilitating their continued occupational adaptation.

### Promoting public education

The fathers regarded it important for the community to share the responsibility for dealing with HIV/AIDS by promoting public education, providing support groups, making counselors available and creating suitable working opportunities for all persons living with HIV/AIDS.

### **Providing accurate information**

The fathers stressed the need for accurate information about HIV/AIDS to be communicated to correct mis-information and to reduce cultural taboo.

### **Providing access to counselors and group sharing**

They expressed their critical need for talking with a counselor or within a support group. They needed to talk and be listened to. Their enthusiastic participation in the group member-checking interview was evidence of this need. At this meeting, the fathers shared their intense feelings of guilt about contacting HIV/AIDS, their fears about infecting their partners and their guilt about participating in anti-retroviral therapy before their ill partners. This new information was given in the presence of a group of men. I surmised there were aspects of the HIV/AIDS illness experience that were more easily shared within a group of fathers. Perhaps the gender of the interviewer (being female) had inhibited the description of some aspects of their illness experience.

### **Creating working opportunities**

The participants required others to facilitate suitable employment for them within the open labour market. Positive attitudes by employers towards persons living with HIV/AIDS and reasonable accommodation within workplaces, was necessary.

#### **4.2.5.3 Transcending fatherhood**

This category describes the father's realization of their mortality and interdependence. Their hopes for living and dying had become specific.

##### **Hoping to continue fathering**

The fathers hoped to be able to continue their fathering occupations and to attain self-realization before they died. Thus they hoped to complete the work of fathering. J hoped to be able to complete his fathering work.

***“Jy glo dis nou tyd om...om alles in te gooi vir jou familie en um kyk dat dinge moet reg is”***

***“You believe that it's the time to...to do your utmost to ensure that everything is in place for the family”***

The fathers also wished to enjoy an extended fatherhood.

***“Die hoop is omdat ek wil sien my kinders groei “***

***“The hope is to see my children grow up”***

A hoped for healing and hoped not to die soon.

***“The hope that one day maybe this thing is...can be healed you see because you never know”***

There was the hope to continue believing in oneself.

***“Sometimes you loose faith, you loose hope when you are in this problem...but we...you have to be strong”***

There was also the hope to obtain paid employment.

***"Yes, now I was busy doing my learner's license, I thought maybe if I can get a license, maybe I go doing driving job...ja it gives me hope, that I'm gonna get a job as soon as I finish"***

### **Accepting human mortality**

In spite of their hopes, each father had reflected on their mortality and wished to be remembered in a special way. These are their expressed epitaphs.

#### **Participant J**

***"En ek glo die pa bewys hom regtig dat um...dat hy wil die rol speel as pa en die kinders moet gelukkig wees en die vrou moet gelukkig wees"***

***"And I believe that the father proves himself that...that he desires to play the fathering role when the children are happy and the wife is happy"***

#### **Participant A**

A desired to be known as an independent father: a person who tried to ***"Help himself"***

#### **Participant G**

G would be immortalized in a book. He explained:

***"Ek voel baie gelukkig...omdat sy 'n boek skryf...vir ander mense (se) wat ek is...dit is sy geskiedenis...hy't dit gemaak"***

***om nie vol pyne te wees nie...om dinge te vergeet om soos 'n gewone mens te voel"***

***"I feel happy...because she (another researcher) is writing a book...that will tell others...this is his history...he did this to alleviate his pain...to forget things, to feel like an ordinary person"***

The existential meaning of their fathering struggle has been brought to their awareness. In the end the fathers viewed themselves as interdependent occupational beings with vulnerabilities and needs. However, this conflicted with their primary motivation for occupational engagement which remained framed within the role of provider to the family in order to be able to meet the family's basic needs'.

**CHAPTER 5: THE DISCUSSION**

University of Cape Town

## CHAPTER FIVE: DISCUSSION

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### **5.1 The macro-context of fathering**

In this section I identify the pertinent societal influences on the occupational adaptation of fathers living with HIV/AIDS and discuss their impact on the adaptive responses and occupations the fathers engaged in.

#### **5.1.1 The occupational challenge**

The occupational challenge (Schkade & Schultz, 1992) that confronted the father's living with HIV/AIDS in this study was the one of continued fathering. The findings indicated that fathering as an occupation of living, is highly valued by the fathers in this study. It is also highly valued by society historically (Lamb, 1987) and presently (Barclay & Lupton, 1999). Within the traditional role of provider, necessary expansions into nurturing and child-caring roles has emanated from shifts towards fulfilling the need to participate equally (to women) in these tasks (Hanson & Bozett, 1986). In the present study, the fathers were available to perform these tasks because they were unemployed. They did not therefore, have to leave home to perform paid work. It was also necessary for them to do this in order to compensate for a partner's unavailability due to incapacity from the HIV/AIDS illness.

In this study social conditions of poverty and health conditions of living with HIV/AIDS appeared to contribute to the fathers being unable to fulfill their main instrumental role of breadwinner.

A striking aspect of the study was of how the limitations of resources impacted on the fathers ability to adapt 'through doing'. This was experienced as having 'nothing' (as expressed by a participant) and therefore, not only being unable to live but also unable to be the fathers they used to be or wished to be. Poverty was not a primary issue of this study when it was commenced. However, this study identified it as a pervading source of conflict to living and to living as a father.

Consciously the fathers expressed their impotence when they did not have the resources (internal and external) with which to adapt and perform their fathering occupations. Internal resources referred to health education and health and social network information. External resources referred to finances, societal attitudes, health and social services for the poor. It must be noted therefore, that the experience of fathering and the occupations of fathering that are performed by fathers who have a different experience of resources, may be different from the experience of fathers without resources.

A major contribution to lack of financial resources for providing for subsistence living, was high rates of unemployment, and the experience of unsuitable work demands and discriminatory employer attitudes. In spite of these obstacles, the fathers in this study persisted with job seeking and career planning. One father planned an adapted career path for himself to fit with his present lack of finances. Another father restructured his work plans by implementing plans for a home-based informal but paid work. Another father survived with social assistance. It appears therefore, that there is a close correlation not only in cause but in the combined impact of poverty and HIV/AIDS for the fathers living with HIV/AIDS and who are poor. This diminished their limited resources even more and placed additional strains on their ability to adapt occupationally.

It is clear that the fathers in this study still considered their primary role to be the one of breadwinner, despite living in poverty and with a chronic illness. This expectation was not buffered by society despite labour legislation to prevent discriminating against persons with disabilities or illnesses. The only buffer available is a disability grant obtained by a means test and this is available for the final stage of the HIV/AIDS illness only. An emotional buffer offered through legislation is the right to confidentiality and voluntary disclosure of one's HIV status by a person. However, as indicated throughout the data analysis, not disclosing prevented access to available resources and this increased the daily conflict for the fathers who were trying to survive living critically in poverty and with illness. Perhaps by regarding the social stigma (surrounding HIV/AIDS and poverty), as a socially-created barrier to accessing available resources, alternative plans for accessing resources and/or creating resources, could be made.

### **5.1.2 Occupational justice for fathers living with HIV/AIDS**

In this study the fathers were constrained from doing the occupations of fathering that were vital to their survival (breadwinning occupations) and were constrained in their choices of what they did and how they did it. Their critical and conflictual conditions of living, unavailability of suitable work in the open labour market and expected and experienced social stigma, constrained these choices. They adapted by retreating from the formal labour sector and planning informal paid and voluntary work and accepting social assistance.

Society has created a paradox in terms of the expectation of the father as the breadwinner when they are ill: they are simultaneously released from the provider role and placed in the patient role.

However, in the absence of providing financial buffers for the ill, society has not negated the expectation of the father as provider for the family. This unsupportive legislation also negated the satisfaction that fathers experienced in performing compensatory occupations of fathering because without financial alternatives, they were still held responsible for providing for their families independently. This would serve to increase their conflict about the need for a changing fathering role and performing different occupations of fathering when the father is ill. The perception created by a society that is dependant on finances to survive is one that regards unpaid work as not valuable to the ill person and to society. Performing paid work however, enabled survival but at the cost of becoming alienated from one's occupational nature because of an underfocus on meaningful occupational engagement. Thus to survive one participant took up 'any paid work'. This work was not meaningful to him but it was important for his survival and the survival of his family.

The legislative and labour systems by being unresponsive to the changing health and survival needs' of fathers, exonerated themselves from their responsibility of caring for the ill and the poor. These societal control mechanisms served to undervalue and thereby neglect the occupational needs of fathers who are poor and ill. In this manner society deprived them of opportunities and conditions of living to promote their health such as outlined in the Ottawa Charter (1986). By failing to create a health-promoting context for fathers living in poverty and with HIV/AIDS, society has failed in its moral obligation towards creating equal and fair conditions for the attainment of health. This in turn could prevent the fathers from becoming contributing members of society because their life's preoccupation will be on surviving survival. In this manner the fathers may not be aware of, or may be inattentive to the needs of his widening environment (Du Toit, 1964).

This may limit their potential for self-realization as occupational beings. This aspect fits the description of an occupational disorder. In order to modify the occupational challenge for these fathers, financial buffers at least, will need to be put into place for them.

### **5.1.3 Quality of life of fathers living with HIV/AIDS**

Two fathers in this study were participating in clinical trials and taking anti-retroviral medication (while the third participant was being prepared to commence with medication during the interviews). They described this positive experience on their bodies and their living. Because taking the medication made them feel well, this motivated them to engage in their fathering occupations. For them, it made the difference between enjoying doing, not doing or doing while feeling unwell. This finding suggests that anti-retroviral therapy for Stages 2 and 3 of the illness did promote satisfactory engagement with occupations with fathering. By contributing to experiences of wellness, it improved the quality of their lives. The South African Government's health focus for the HIV/AIDS epidemic remains, in contrast with these findings and diverse lobbying efforts, on prevention through vaccine development, mother-to-child preventative programs and for victims of rape. Access to anti-retroviral drugs that are reported to contribute to prolonged lifespan and improved quality of life, is constrained to persons volunteering to participate in clinical trials or those who are able to afford the drugs. This legislation creates unequal and unfair opportunities for engagement in occupation and creates the perception of an uncaring and uncompassionate society.

## **5.2 The micro-context of fathers living with HIV/AIDS**

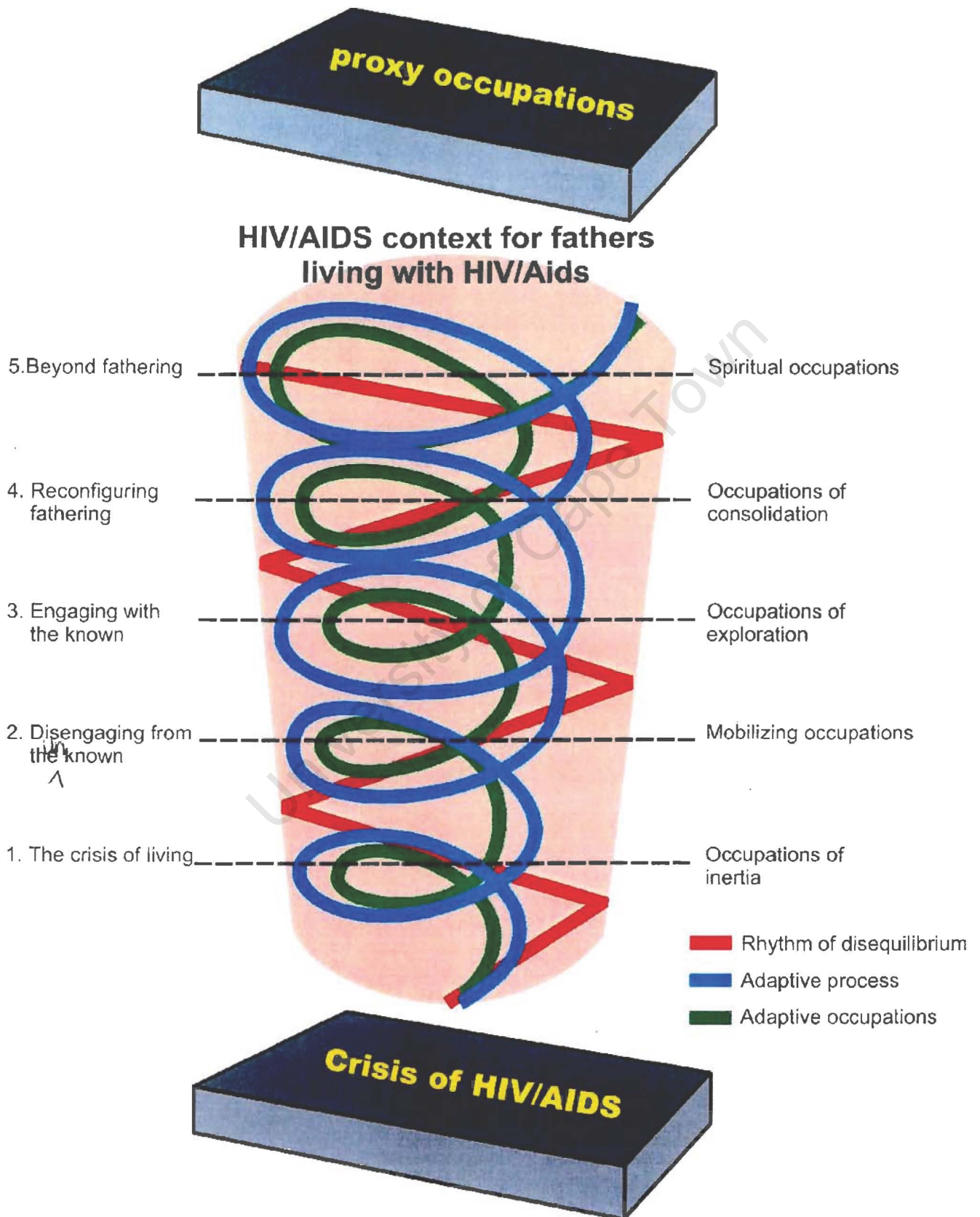
Given the scope and severity of the occupational challenge on fathers living with HIV/AIDS, we need to ask if the fathers in this study did adapt and how they adapted occupationally?

### **5.2.1 Model of occupational adaptation**

A model of occupational adaptation was developed to illustrate and describe the occupational adaptation experience of fathers living with HIV/AIDS in this study. The model depicts the rhythm, process and occupations of adaptation the fathers engaged in while adapting to their illness.

The model is based on the Model of Creative Ability (Du Toit, 1974) and incorporates concepts derived from the generic model of occupational adaptation (Schade & Schultz, 1992), as well as the view by Frank (1996, p. 48) of occupations as 'chunks of activities' and adaptive responses 'nestled' within adaptive systems. The model clearly depicts occupational adaptation experience as a process of occupations unfolding within occupations and core adaptive occupations are performed within other core occupations. For example, the adaptive occupation of 'disengaging from the known' is characterized essentially by 'mobilizing occupations' i.e. the things the fathers did to propel themselves forward towards adaptation. The adaptive process too depicts levels of adaptation upon levels of adaptation. For example, the levels of the process of adaptation, specifically the adaptive level of the personal-family context operating within the next level of adaptation namely, the community and work contexts. The Model of Occupational Adaptation derived from the findings of this study is illustrated below.

# Model of Occupational Adaptation



### 5.2.2 The crisis of HIV/AIDS

This health crisis pervaded all the dimensions of living and occupations of fathering for the fathers in this study. These included the dimensions of spirituality, economics, health, work, family life, community life, temporality, child-rearing and relationships with partners. Some occupations of fathering were stopped, others altered and some new ones were created.

The requirement of having resources, activities and flexible routines available for adaptation (Frank, 1996), was met firstly within the father's **personal-family context**. It was within this context that they felt secure enough to disclose their HIV positive status to a partner or close relative.

Within this context of established trust and confidentiality, the fathers applied generic adaptive occupations to adapt to their illness. These occupations appeared to coincide with the sequential development of creative ability. The model of creative ability as outlined by Du Toit(1972) best described the process the fathers used to engage with occupations of fathering for adaptive purposes because it enabled me to understand what resources and core adaptive occupations they used and how they used them to be able to continue their fathering trajectory.

What appears to distinguish this model from other models that are demarcated with stages, for example the Kubler-Ross (cited in Sue et al, 1990) stages of grieving, is that although the occupations of adaptation appeared to develop sequentially, this did not preclude a reversal to a previous level or to the beginning of the sequence, whenever the father experienced a daily crisis.

This implies that occupational adaptation occurs in adaptive loops to enable the father to manage a crisis. This also suggests that the process and type of adaptive occupations used may be generic to fathers in this study and to other persons with a similar experience.

What was very apparent was their expressed inability to control and influence the community and paid working contexts. So although they adapted within their personal-family contexts independently, they asked for assistance to negotiate their engagement with the next important adaptive level, namely the community and working contexts.

### **5.2.3 The rhythm of adaptation**

The fathering experience for the fathers in this study was characterized by a constant **rhythm of disequilibrium**. This appeared to be the result of living critically in poverty and with the HIV/AIDS illness. It propelled daily living into an ongoing state of emotional, physical and environmental flux.

Living with HIV/AIDS was a crisis superimposed on the crisis of living in poverty (At the beginning of the study I was unaware that the participants lived in poverty and that poverty would play a major role in their ability to adapt occupationally, to the HIV/AIDS illness). These conditions of living conflicted with and aggravated each other simultaneously. Decisions and choices were two-fold and dichotomous only i.e. either/or, and were weighed up carefully as they always held life and death consequences. For example, accessing basic services to ensure continued living, required disclosing one's HIV/AIDS status.

However for the fathers, this may result in rejection of care and prevent access to necessary services and paid working opportunities. The fathers also needed to consider whether to work or to rest. Working to earn a living would sustain their need for daily food and shelter while resting (although required by the sick body) did not.

The discourse of rhythmic disequilibrium as experienced by the fathers throughout this level of occupational adaptation, corresponded well with the second level in the development of creative ability and adaptive responses, namely, the level of self-differentiation (Du Toit, 1974). This refers to the level of development in creative ability or the development of the ability to engage with the environment and describes the corresponding quality of that engagement with the environment. At this level of self-differentiation the person is separating himself from something else. For example, separating the known from the unknown or the new from the old.

Throughout the fathering experience at this personal-family level, the father was faced with two dichotomous choices of which both had life-threatening consequences. The choice was of having '*something*' or '*nothing*' (as described by a participant) or between living or dying. These choices conflicted with each other and because they both had life and death consequences, sustained the disequilibrium that the fathers in this study experienced on a daily basis.

Furthermore, the fathering experience alternated between periods of critical disequilibrium (for example when they considered whether to commit suicide or not) to periods when the disequilibrium became more rhythmic.

The adaptive occupations appeared to be nestled or fixed within this level of self-differentiation in the development of creative ability. So although they attained an experience of self-realization towards the end of their experience with the crisis of living with HIV/AIDS, they had made only tentative independent attempts to participate with the broader community and working contexts. To fully adapt within these contexts the fathers in this study requested for others to assist them.

#### **5.2.4 The constraint of social stigma on the adaptive response**

The social stigma surrounding HIV/AIDS constrained the adaptive response by inhibiting the fathers' engagement with the environment. This threatened the existence of the fathering experience because it stopped them from asking for assistance from others, be it their immediate or extended families or friends.

In order to maintain the status-quo the fathers needed to engage in quasi-compensatory occupations such as deception, and pretence by keeping up appearances. They pretended to go to work and pretended to feel well to sustain the previously established support of family and the community.

Their experiences of disclosure were negative outside of the immediate family. They experienced that they were accepted or rejected depending on how well they disguised their true feelings and working occupations. For example, they pretended to be well fathers and they pretended to go to work in the mornings –while they were actually attending the Research Unit.

Because of the longevity of the illness and the enduring social stigma trajectory that needed to be managed, this meant that authentic fathering and authentic personhood was threatened.

In other words, they could not evolve their own fatherhood identity but needed to conform to society's prescription of fathering. Over time, this would also make them susceptible to occupational disorders because within an unchanging adaptive context, the fathers may need to continue to engage in quasi-compensatory occupations to the neglect of authentic or meaningful occupational engagement.

#### **5.2.5 The personal meaning of fathering**

Central to the fathering experience for fathers living with HIV/AIDS was the aim not only to continue being fathers but to become their idealized fathers. Thus their occupational adaptation was directed towards meeting this life goal (Larson, 1996). Fathering met their life's purpose, made them feel important and valued by their families and by their communities. One participant expressed this sentiment succinctly:

***"It feels to me as if...it feels to me, I feel important and I feel well and I can still do things. Yes I can still be a father"***

The fathers described their view of health and well-being – as feeling well and important when they are still able to do things i.e. to be occupational beings. Because it was affirming to be acknowledged by society, the aim of being a father and continuing to be a father ensured continued congruence with and acknowledgement by others. Fathering was therefore a culturally important role and made the fathers in this study feel important.

The HIV/AIDS illness (perceived by society as an unacceptable disease) threatened continuing fathering because of increasing incapacity and because the fathers in this study, needed support during a prolonged chronic course of illness. The cost of disclosure and potential support or rejection was weighed up against the need to continue to feel important, valued and supported. The loss of current acceptance was experienced as a greater threat than uncertain support if one disclosed one's HIV positive status. So the participants chose not to tell or to tell selectively.

### **5.2.5 The constraint of role prescription**

The data analysis indicated that fathers living with HIV/AIDS considered their primary function to be the breadwinner of the family. This attitude remained unchanged in spite of making occupational adaptations in which their fathering occupations became expanded and they realized their importance and experienced satisfaction in doing them. Lamb (1986) recorded that the conceptualization of the father as the main breadwinner endured from the mid nineteenth century to present day. According to the participants, they still experienced the main function of fathering to be the provider. Therefore, modern politico-economic influences that attempt to equalize gender disparities in the workplace have not changed. The working contexts and current legislation was found not to support the changing role of the father (Hanson & Bozett, 1986). Society therefore has continued to overvalue this function of the father and simultaneously by not valuing unpaid work, demonstrates its devaluation of other fathering occupations.

For example, the findings indicated that fathers did experience satisfaction in performing additional fathering occupations such as child-care and domestic tasks. In addition, the fathers created alternative formal work (unpaid work) for themselves such as religious instruction or psycho-education of the immediate community. They managed to organize this work around their child-care and domestic work. It appears therefore that fixed societal attitudes supported by institutions and legislation, prescribe the main role of the father and this prevented fathers from expanding the range of their fathering occupations and experiences because these were not congruent with dominant societal values.

It is my perception that in spite of legislation aimed at equalizing salaries and management positions between men and women in the marketplace, market conditions have not accelerated to fit this legislation yet. In this manner the fathers in this study experienced being held responsible for the survival of their families irrespective of whether they were poor or ill. Lamb (1987) emphasized that this dominant patriarchal attitude had persisted over the past one hundred and fifty years already.

#### **5.2.6 The constraint on the development of creative ability and adaptive responses.**

The fathers in this study experienced an occupational development that was constrained within the second level of the development of creative ability, namely, that of the level of self-differentiation. This may suggest that living in combined conditions of illness and poverty precludes further development unless appropriate interventions are made that facilitate access to the next adaptive context.

This places this population at high risk for experiencing occupational disorders. This may also contribute towards 'skewed' development and an inability to attain full self-realization. In this study, the fathers developed their occupational adaptation responses perpendicularly to the usual course of parallel development that is indicated in the model of creative ability. This may imply that achieving self-fulfillment requires negotiation through different adaptive contexts because the conditions for engaging with adaptive contexts are not equal for all persons. Therefore, it becomes necessary to facilitate these negotiations. This required that proxy occupations be performed by someone in order to create conditions of living that are conducive to occupational adaptation for the fathers in this study, for the next adaptive level, namely the community and working contexts.

### **5.3 Adaptive occupations embedded within adaptive occupations: process and response**

The findings indicated that an integral aspect of the fathering experience was that through daily and ordinary occupations, they engaged in two types of generic adaptive occupations: the one is process-based while the other is response-based (adapted from Du Toit, 1974). These adaptation cycles overlapped and were nestled within each other.

Spencer et al (1996) described the occupational adaptation process as comprised of three components, namely environmental occupational forms, personal occupational forms and the processes of change that governs the interaction between the two. These occupational forms or occupational contexts and processes, shape and influence the occupations that are performed (Nelson, 1988).

Thus in this study, the experience of fathering was embedded within a specific HIV/AIDS context that determined the occupational forms and occupations of fathering. This phenomenological context governed the conditions for occupational adaptation. The occupational form is the result of configurations of occupation that are specific to the fathers living with HIV/AIDS. In this study these configurations were generic adaptive occupations namely, process-based adaptive occupations and response-based adaptive occupations. The process-based adaptive occupations and their corresponding response-based adaptive occupations are outlined as they unfolded from the data analysis.

### **5.3.1 Adapting to the crisis of living – Occupations of inertia**

Within this first adaptive occupation the crisis is brought about by the strain of conflicting needs and the unavailability of the resources needed for adapting to living in poverty and with a chronic and life-threatening illness. The crisis of living for the fathers living with HIV/AIDS was about creating order out of the emotional chaos and about finding the inner or outer resources to be able to adapt to their new living conditions.

The catalyzing factor within this adaptive occupation is for persons to attend to, become aware of and to feel secure (Du Toit, 1974). The fathers achieved this covertly by continuing their familiar daily routines and fathering occupations within the home setting. While performing these occupations, their thoughts were preoccupied with many present and future concerns. I refer to these thinking occupations as occupations of inertia i.e. routine occupations that offered space for 'being-in-doing' and reflecting (Wilcock, 1998).

This adaptive context provided a holding function during which the fathers were able to attain some internal equilibrium. This provided the impetus to begin knowing about and responding to their new lives.

Occupational adaptation was limited by the threat of rejection and isolation by family and community members. Thus the fathers needed to maintain acceptance and access to limited care by concealing their daily pain and HIV positive status and pretending to continue with normal occupations of fathering. It was possible to conceal their illness because during stage 2 and early stage 3 of the illness trajectory, the illness was still largely invisible.

Unfortunately, by managing the stigma in this manner, the fathers denied their true experience of the illness. Frank (1991, p71) concluded that: "They deny that to be human is to be mortal, to become ill and die". In taking on this position, the fathers colluded with society and their negative view of persons with HIV/AIDS and persons with illnesses.

In contrast, being accepted by society promoted authentic living and adaptation, while the threat of rejection and further denial of opportunities to earn a basic living, coerced the fathers into applying quasi-compensatory occupations in order to maintain the status-quo. For example to keep up appearances of normality, one participant would leave home at the usual working time, in order to attend the Research Unit. Appearing normal and living normally by performing normal occupations of fathering became the baseline from which to begin to explore their new identity as a father living with HIV/AIDS.

The initial phase of adapting to the crisis of living, entailed gaining cognitive and emotional awareness of what it is like to live without the things that are necessary for survival and illness. The dilemma of fathering was whether they could continue to be fathers while being unable to be the sole breadwinners and being able to provide for the families daily, sustenance and medical needs. They described the internal struggle and preoccupation with this issue as they continued to grapple with it.

The basic premise of adaptation is that a person has resources to use to adapt. And adaptive capacity refers to the range of resources and activities within a given socio-cultural context that a person has at his disposal for adaptation purposes (Frank, 1996). The fathers in this study were unemployed and did not have the financial resources to cover their subsistence living nor their medical emergencies. This reduced their adaptive capacity and their choices for adaptation to life and death choices with life and death consequences. For example, it was necessary consider buying daily food as opposed to having transport money to travel to the nearest clinic or hospital for treatment for a child.

Being poor was also associated with living without essential information about resources that could assist their adaptation. These conditions of living and adapting constrained their interactions with their environment. This constrained their autonomy and prevented them from assuming responsibility and taking control of their illness. In addition, it was more acceptable to be regarded as a poor person than a person living with HIV/AIDS because family support was ensured when one was unemployed, but it was threatened when a person carried a disease.

In this study it was found that fathers continued to desire to fulfill their fathering role, especially income-generating occupations. This expectation to be independent providers was congruent with societal values. However, society failed to support the basic financial, medical and occupational needs of ill and poor persons by not creating financial and occupational alternatives for them.

Due to the stigmatizing nature of their illness, the fathers lived without the acceptance, understanding and support of society at large. This inhibited their interactions with the environment because they risked increasing alienation if they disclosed their HIV positive status. Deceptive relationships were established to negotiate and control potential negative relationships and rejection. These compensatory occupations aimed to maintain pseudo-positive relations for adaptive purposes. Without these, the father's role in the community and within the family, risked becoming threatened or extinct. Thus the social stigma surrounding HIV/AIDS disease endangered their occupational adaptation towards continued fathering.

Because the fathers regarded their primary role as a provider and breadwinner, the need to fulfill this fathering occupation remained unchanged. In fact, it was reinforced with the onset of the illness, because it highlighted their basic need to care for their sick bodies and to prevent them from dying. Some of the despair they experienced was in their inability to generate income for the family's survival and medical needs. They adapted to this situation by eating sparsely and unhealthily. They withheld information about their HIV positive status from family and friends, in order to be able to continue to receive their emotional and material support.

Besides using ongoing survival occupational adaptations to meet their needs for food, shelter and medicines, the participants wished to enlist material help from other sources, but did not have the necessary information to do so. This finding suggests that adaptation may depend on internal resources that enable the person to source the information for themselves. In this study the fathers lived without information about available resources and this perhaps compromised their occupational adaptation.

The fathering experience included making sacrifices by hiding one's authentic self. This set up conditions for acceptance, inclusion and positive relations. For the fathers, access to emotional care and acceptance within the family and community was obtained at the personal cost of pretending that they were normal and were not ill. Frank (1991, p68) described this process as one in which "we make our 'best deal' of behavior to get what we need". In other words, the participants had reflected on what they would lose if they disclosed their HIV positive status. This created a double constraint because medical resources (access to anti-retroviral therapy for these fathers) was available only when the father made an admission about his HIV positive status. Family support was uncertain in light of the pervading fears of contagion. Community support was not possible because of current negative attitudes towards persons living with HIV/AIDS. In essence the inner and outer resources to manage adaptation were minimal and placed these fathers and their families in circumstances that daily threatened their existence. Fathering within this HIV/AIDS and poverty context was a daily struggle to make ends meet and to survive daily medical crisis. The fathers became preoccupied with their concerns and spent much time 'thinking' (as described by a participant).

The struggle of daily living with the illness augmented the father's feelings of social isolation and feelings of hopelessness because they felt they did not have the resources needed for adaptation. In order to be able to continue their occupations of fathering, the father's applied real compensatory and quasi-compensatory occupations to be able to control and maintain the support they had from their families and communities. This was their strategy to retain their autonomy. In this process they sacrificed authentic living and relating for attitudes of acceptance and inclusion.

### **5.3.2 Adapting by disengaging from the known – Mobilizing occupations**

Within this adaptive occupation the fathers engaged with the unknown, namely the new illness. The purpose was to separate themselves from their crisis in order to adapt. I have referred to these adaptive occupations as mobilizing occupations because they required active engagement with the environment.

The fathers adapted to the unknown by obtaining information about the unknown: they sought to have their diagnosis confirmed and to know about their illness. They did this by making contact with the public medical system that was at their disposal. After having their diagnosis confirmed they immediately wished to engage in self-destructive actions. However, they resisted this and chose to familiarize themselves with living with the illness tentatively. Thus they decided to live, to know, and to accept the illness. The occupations here are characterized by a doing in order to gain vital resources that can extend their choices for adaptation.

The doing by the father is important here because it stimulates a "concept of self as handler: 'I ....it'" (Du Toit, 1974). In this sense the father regained some of his self- agency.

Needing to be accepted unconditionally at this stage, but having difficulty dealing with the anxiety that the knowledge of the HIV positive status had induced, elicited telling the first person (usually the partner) impulsively. However for one participant, telling his sister first enabled him to plan and prepare for telling his partner about his HIV positive status. This enabled him to approach her sensitively.

### **5.3.3 Adapting by engaging with the unknown – Occupations of exploration**

In order to disengage from the known the fathers needed to engage with the unknown by beginning to discover or enquire about living with illness. Du Toit (1974, p. 67) said " it is necessary to know about, in order to make". Thus they began to explore what living with HIV/AIDS is about. I refer to these occupations as occupations of exploration.

Because their anxiety was still experienced as fear or anger, they began to explore their fears about living and dying with this illness. The experience of learning about the implications of their illness required that the nature of their enquiries be as broad and in-depth as possible. This would strengthen their tentative sense of security about living with HIV/AIDS.

The occupations applied to achieve this goal were self-reflection, formal discussion with health professionals, and informal conversation (talking and listening) with selective family and friends.

These selective information-gathering and interactional occupations enabled them to assess the likelihood for positive approach behaviors and acceptance and inclusion within the community. To be rejected by the community was considered to be a life-threat to their continuing fathering experience.

The occupational nature of their adaptations here, although exploratory, included solitary and contemplative activities because of the constraints placed on them by the social stigma associated with the disease. Alone, the fathers reflected on the implications that living with this illness had for their future and the future of their family. As a result, the fathers experienced renewed disequilibrium as they faced conflicting and dichotomous fears about living and dying with HIV/AIDS. They engaged in negative adaptations such as concealing their HIV positive status in order to achieve the long-term outcome of acceptance (Larson, 1998). Normality was maintained by keeping to temporal routines within the family-related activities. It was also maintained by regular job-seeking and peer discussions about negative job experiences.

#### **5.3.4 Adapting by reconfiguring fathering – Occupations of consolidation**

Here the fathers realigned their adaptations with their fathering trajectory. They did this by re-configuring their fathering. I refer to these occupations as occupations of consolidation because they integrated old occupations of fathering with new ones. Through adapting while doing, namely, continuing with their familiar fathering occupations but engaging with new fathering occupations, they re-configure that they can continue fathering.

These adaptations were performed on a pre-conscious level (Frank, 1996) so that the fathers described that nothing had changed when in fact everything had changed. During this adaptive occupation, the father's new identity as a father living with HIV/AIDS became consolidated.

Here adaptations were made constantly to deal with the conditions of living in physical, emotional and occupational flux. So although the fathers gained experience of new fathering occupations, their range of experiences was constrained by the internal conditions of living in flux, for example, the experience of fluctuating pain. This would have an inhibiting influence on their ability to participate in occupations and may deprive them of engaging in occupations of fathering because of reduced and fluctuating capacity. In addition, the fathers reported performing additional occupations to compensate for the ill partner's fluctuating and reduced capacity. This compensatory trend fitted well with the modern view of parenting (Barclay & Lupton, 1999). This adaptive occupation entailed a focus on doing occupations in order to restore the fathering trajectory so that they could become the fathers they wanted to be.

Through the acquisition of self-practiced new skills they realized they could still be fathers. This contributed to a new awareness that they could continue to be fathers. At this stage of adaptation, the fathers experience the parameters for living as a father with HIV/AIDS. For example they began to realize that their time was limited and uncertain. They also began to understand the personal sacrifice of denial they needed to make, in order to continue receiving acceptance from their families and communities. Thus they had established the norms for living as a father with HIV/AIDS. This knowledge was important for further adaptation.

The findings of this study indicated that fathers living with HIV/AIDS were engaged with all three dimensions of occupation, namely doing, being and becoming (Wilcock, 1998). They identified fathering occupations as those pertaining to providing financial, physical and emotional support to their children and partners. Of these occupations the breadwinning aspect was the primary one. During the interviews they described their engagement with contemplative, relaxing and meaning-creation occupations: these enabled them to adapt to their illness and to continue fathering. However, they were unaware of having done so. Frank (1996) supported the view that effective adaptation occurred on a sub-conscious level.

#### **5.3.5 Adapting beyond fathering – Spiritual occupations**

Within this adaptive occupation, the fathers described the internal and external adaptations that were necessary to sustain and promote their fathering trajectory. They referred to internal adaptations as the things they could do and to external adaptations as the things others could do. Both were regarded as necessary to further occupational adaptation.

In addition, the illness allowed them to engage in meaning-creation occupations or spiritual occupations. Through reflection, they considered who they were and what they could become. This facilitated a level of self-acceptance and gave them hope to become the fathers and also the persons they wished to be. Hence, their identity as an occupational being had emerged. There appeared a subconscious acknowledgment of their human frailty and their identity as occupational beings. Through these occupations, they reached an understanding about their mortality and their limitations.

Because they experienced the ongoing need to provide financially for the family, paid working occupations formed the core occupation within the fathering experience for them. It became more so when living with the HIV/AIDS illness because medical needs were acute and critical and involved additional family members including children. However, the fathers felt unable to access the working contexts because they would be discriminated against and because they required selective-type work to suit their physical abilities and the formal labour market did not accommodate these needs. By being unable to work or being unsuited to work in the open labour market, they felt they had nothing to contribute to their children and families.

The fathers in this study required support and the experience of sameness with similar others to reduce their anxiety about their illness for example, counseling or support group's. This was evident from the positive response made within the group member- checking interview. The fathers expressed the critical need to give and receive support within a support group. This resource was available to them but it was not accessible because they could not afford the transport fees to the venue where the support group was held.

They also regarded their personal experiences as valuable and felt that these, when shared, could contribute to facilitating adaptation for others. The adaptive impact of participation in such a group would serve to increase the father's self-esteem so that they could be encouraged to engage in the next level of adaptation, namely the community and work contexts.

#### **5.4 Proxy occupations**

I refer to these occupations as those that another person or the occupational therapist needs to engage in, in partnership with the client until the client "*can gain more control in his or her environment*" (Frank, 1996, p. 50). Metaphorically, it can be aligned to as 'building bridges' towards occupational adaptation and self-realization.

Illness by its very nature places a person in compromising relations with medical resources because they are assumed to 'know best'. Ill persons are usually released from their working and cultural responsibilities. Surviving the illness is all-important and frequently, regarded as proof of 'worthiness' and justification for re-entering the labour market and re-joining cultural activities. Chronic illness however, frequently precludes a re-entry to the system of paid work.

Therefore, is it reasonable to expect poor persons living in a developing country, who have no financial buffers, to continue providing independantly for their basic needs? Furthermore, we need to ask if, and how the chronically ill person and the father living with HIV/AIDS can experience health and well-being? In order to advocate for social and occupational justice, it appears that the occupational therapist needs to engage in proxy occupations. These will facilitate the access within the next, pertinent adaptive system for the client. The findings of the study also indicated that performing proxy occupations may become the bridge to further development of creative ability and self-realization.

In other words, although the fathers in this study directed their own growth and competence as fathers in the personal-family context, they were not able to continue fathering within the next adaptive level (Community and working contexts) without the assistance of someone performing proxy occupations for them.

In this study, the father's occupational adaptation was constrained within the second level of creative ability, namely that of self-differentiation (Du Toit, 1974).

The findings of this study appear to suggest that occupational adaptation may progress in adaptation loops with each loop representing a step in the continuum of occupational adaptation for a person. Frank (1996) referred to this phenomenon as "nestings" of adaptive systems. Thus the fathers' living with HIV/AIDS first attended to adapting within their immediate and personal context. Thereafter, they recognized the need to attend to adaptation within a broader or outer context, namely in relation to their extended families, communities and lastly, the working context. To enter these potential adaptive systems however, they requested the assistance of "others" or outside agencies. These agencies would serve the purpose of acting as surrogates or proxies on behalf of the fathers living with HIV/AIDS (Frank, 1996). Their aim would be to empower persons to enter these systems. I refer to these occupations as proxy occupations. When father's living with HIV/AIDS experience such disempowerment, it calls for a person or organization to act as proxy on behalf of them. This requires the availability of an outside agency and it requires having access to one. The role of the outside agency is to modify and facilitate the adaptation context so that it matches the father's current adaptive capacity. In other words the occupational challenge becomes modified to fit the father's adaptive capacity.

This view is congruent with the prescribed role and sequel of actions required of the occupational therapist practicing within the Model of Creative Ability framework (Du Toit, 1964). In this model the occupational therapist is required to establish safe, secure and appropriate adaptation contexts for occupational adaptation. Pizzi (1990 p. 200) in recognition of this specific role of the occupational therapist stated: "Occupational therapy can become the role model for the creation of safe and secure environments in which persons with HIV can live, work and function". The findings suggests that further occupational adaptation for the fathers living with HIV/AIDS is dependant upon another person pre-empting their continued occupational adaptation by performing proxy occupations.

In addition, the data analysis suggests that with each new crisis the person would re-enter the adaptation loops from the beginning and proceed through the same process. Therefore, it is suggested that the adaptive occupations may be generic and could be applied within each new crisis.

#### **5.4.1 Proxy occupations recommended by the participants**

This describes the things others could do to enable the fathers with HIV/AIDS to continue their fathering occupations as voiced by the participants.

##### **5.4.1.1 Listening to the ill**

The fathers described their critical need to talk to others. They experienced this as cathartic and it distracted their inner preoccupations and anxieties about their futures or lack thereof.

This is a proxy occupation that could foster self-understanding, a feeling of belongingness and acceptance. However, this potential resource was highly conditional - it could threaten their existence if others decided to reject their illness or it could support their illness if they were accepted. The outcome of telling was always unknown and unpredictable. It is under these constraining conditions of engagement or relatedness within the adaptation context that fathers living with HIV/AIDS take the initial step towards adapting by re-aligning their fathering occupations to course towards the ultimate meaning fathering has for them. Frank (1991, p127) confidently guided personal and societal attitudes towards a positive and compassionate relatedness when he stated: "The responsibility of the ill, then, is not to get well but to express their illness well". This wisdom suggests that the ill and the non-ill have a mutual responsibility: the former are required to find individual and organizational means to express their illness experience and their need's honestly, while the latter have the responsibility for assisting to put mechanisms in place to support the living of all ill persons.

The findings from the data analysis showed that the fathers had no affordable access to participating in discussions where they could express their illness and reflect on it. These occupations of being-in-doing and becoming-in-doing (Wilcock, 1998) that were necessary and important for fathers living with HIV/AIDS, are therefore undervalued by society.

#### **5.4.1.2 Opportunities for meaning-creation**

It appeared that the struggle of daily survival for these fathers was redeemed inadvertently by their illness because it forced them into establishing the ultimate purpose and meaning of their fathering for themselves.

Without the assistance of support groups, they engaged in meaning-creation occupations. Presti (1990) explained that the onset of HIV/AIDS became a spiritual experience for many persons. She said "it transcends what is trivial and grasps at the eternal and that which lies beyond" (Presti, 1990, p87). Thus while the experience of living in poverty could fixate human growth and occupational development into a preoccupation with doing in order to survive, it appeared that the overlap with a terminal illness such as HIV/AIDS thrust the human spirit towards locating the center of existence with a consequent re-prioritizing of one's life goals. In this manner, the adaptation opportunity was created for the father living with HIV/AIDS to become aware of the person he desired to become. So the impetus for making occupational adaptations became accelerated for them. Occupational adaptation included occupations of being-in-doing for example, reflecting by contemplating and talking to others, and becoming-in-doing for example meaning-creation occupations (Wilcock, 1998) such as adjusting the fatherhood ideal and creating hope.

Although both Pizzi (1990) and Presti (1990) refer to the occupations of meaning-creation during the terminal phase of the HIV/AIDS illness, it is apparent from the data analysis that the participants engaged in meaning-creation subsequent to receiving the diagnosis. This suggests that meaning-creation occupations or spiritual occupations may be integral to the adaptation process throughout the four stages of the HIV/AIDS illness.

## **5.5 Issues for occupational therapy practice**

Traditional local practice has been focused within a curative model whereby the components of functioning have been improved for engagement in occupation. Practicing within different health contexts has provided challenges for the development of alternative practice models in occupational therapy. Rehabilitation goals needed to be redefined (Watson, 1997). This study was pursued with the intention of possibly identifying a local model of practice suitable for South Africans. The findings of this study indicate that the goal of occupational therapy and the scope of practice required reconsideration.

### **5.5.1 Rehabilitation without medication (ARV)**

Rehabilitation is considered to be an adjunct to recovery for some medical conditions. Occupational therapy interventions are usually pursued in conjunction with pertinent medications for specific conditions in order to achieve the best health outcome. The participants in this study expressed a positive outcome when taking antiretroviral medication as part of the clinical trials they had voluntarily participated in. However, for the majority of South Africans currently (who live in poverty) this option is not available to them because it is limited. Without the hope of medicines to control the illness, it means that most cases of persons with HIV/AIDS will be unreported and therefore, these persons will only make contact with rehabilitation services as a result of another medical condition. It also implies that the anticipated time of referral will be during the later stages of the illness when the illness is observable.

This will limit occupational therapy interventions to the final stages of the HIV/AIDS illness for persons with the illness and to preventative measures for persons at risk for infection. This implies that occupational therapy interventions aimed at promoting the quality of life of fathers with HIV/AIDS (Stages 2 and 3 of the illness) by meaningful and satisfactory engagement with occupations of fathering, will not be done. In contrast, occupational therapy interventions reported from developed countries are essentially aimed at those stages. This difference in client population and unavailability of ARV therapy, directs local occupational therapists to pursue a different goal for rehabilitation.

#### **5.5.2 Role Theory Constraints**

The findings of this study indicate that occupations of fathering are many, diverse and need specific within the personal-family contexts. This appeared to be congruent with the partner and family expectations. Within the broader community and working contexts however, the father's role was regarded to be function-specific and constrained to a breadwinning function. This function was central to fathering when the family was poor and ill. Only this aspect of fathering was endorsed and rewarded financially. It may therefore be necessary for the occupational therapist to negotiate this attitudinal and policy shift on an organizational level in order to support the father's survival and occupational needs especially when he is poor and ill.

This finding also indicates that occupational therapists need to be aware of the diverse occupational needs of fathers in general and of fathers living with HIV/AIDS who are poor.

The risk of reinforcing existing occupational injustices through non-intervention in their daily experiences of occupational deprivation or occupational alienation for these fathers is very high. The challenge for local occupational therapists is to promote continued involvement in occupations of fathering by engaging with work organizations for restructured work. It is also necessary for them to facilitate institutional financial alternatives and comprehensive social assistance, so that fathers living in poverty and with illness can engage in occupations of their choice with dignity and not with shame or guilt.

### **5.5.3 A suitable practice model**

In this study I have successfully applied an adapted form of the model of creative ability to describe and discuss the experiences of fathers living with HIV/AIDS. This model has enabled me to understand the influences on what they do and how they do it, in order to continue engagement with their occupations of fathering. The model also assisted me to understand the constraints on their occupational engagement, occupational development and occupational adaptation. Perhaps this adapted model may be useful in understanding the occupational context available for occupational adaptation, for fathers who are HIV positive (or fathers with illnesses) and fathers who are poor and live locally. The model is able to highlight the constraints of the adaptive context for occupational adaptation. This in turn identifies the focal point for intervention for this population clearly.

#### **5.6.4 Shifts in intervention**

The findings of this study indicate that within the personal-family context, the father living with HIV/AIDS was engaged with many and diverse occupations of fathering, despite having only scarce resources. This implies that their engagement in occupations of fathering was not problematic within this context. The findings indicated that the fathers were however, unable to access the next important adaptive level, the community and working context, independently. Thus occupational adaptation in this context was problematic for them. This finding suggests that for these fathers accessing another adaptive context required the assistance of a proxy, acting on their behalf. Hence the role of the occupational therapist within a local context and for this population may not be to facilitate occupational engagement but to facilitate occupational adaptation. She may do this by modifying the occupational challenge through promoting the adaptive capacity of the occupational context or the fathers living with HIV/AIDS (or with illnesses or in poverty). These fathers are at risk for not realizing their potential and reaching self-fulfillment because their adaptive responses are constrained by unresponsive adaptive contexts.

#### **5.6 Limitations of the study**

This refers to the parameters of the study. This present study was limited by:

that were easier to discuss in the company of other men, for example, personal feelings of guilt. Thus during the member-checking group interview, the fathers added new information to what had appeared to be 'saturation of information' during the initial interview. It may therefore be necessary to augment the individual interview with a group interview, in an enquiry of this nature.

#### **5.6.4 Medical intervention**

The findings of this study cannot be applied to fathers living with HIV/AIDS who are not on anti-retroviral therapy within a clinical trial setting. The Research Unit provided not only hope for living for the fathers and partners, but also provided practical access to this service by paying all their transportation fees.

Although legislation has now been passed allowing all state facilities to provide anti-retroviral therapy for all HIV positive, pregnant mothers and rape victims, the legislation (by its preventative focus), does not include fathers or other persons living with HIV/AIDS. At present therefore, participation in clinical trials remains the only access to anti-retroviral therapy for fathers living with HIV/AIDS and for persons who are unable to afford them or are not privately sponsored.

#### **5.6.5 Diversity of resources**

The experience of fathering described by the participants in this study is specific to fathers living with scarce resources. The findings may not be similar to fathers who have more resources.

### **5.7.6 Additional ethical considerations**

These are additional considerations to be considered when research participants are living in poverty and with illness.

#### **5.6.6.1 Financial remuneration for participants**

Within the current context of the HIV/AIDS epidemic in South Africa and the associated high rate of poverty, financial remuneration for participating in research projects becomes a primary consideration for all participants. This may be the social responsibility of all research that includes persons living in poverty and with HIV/AIDS. Furthermore, participating in research projects may be considered as a work because a participant is selected carefully, a contract is entered into, and the participant is committed to being productive and fulfilling his part of the contract.

Although the participant may inadvertently gain something from this process, it is not guaranteed, nor is the reward usually a financial one. Considering that these persons are dependant on survival living, financial remuneration may be the only viable, human response from a researcher.

#### **5.6.6.2 Ethics of clinical trials**

The risk of worsening immune suppression is reduced by using anti- retroviral drugs. This contributed to an enhanced feeling of wellness. In this study the participants expressed this health outcome. Participation was enabled through the Research Unit's payment of all transportation fees. Without this, participation would not have been possible.

This finding suggests that the financial barriers to accessing available health services and other services for persons living in poverty and with illness need to be overcome by the State or private organizations by subsidizing transportation costs. The failure to do so may be considered as unethical practice.

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**CHAPTER 6: CONCLUSION AND  
RECOMMENDATIONS**

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### **6.1 Conclusion**

The findings have indicated that occupational adaptation for the fathers living with HIV/AIDS in this study is arrested within the second level of the development of creative ability, namely the level of self-differentiation. The two main reasons for this are the lack of basic resources and the climate of exclusion that is generated by poverty and social stigma. Because the fathers valued fathering, they applied self-direction to adapt the occupations of fathering within their personal-family context so that they could continue fathering.

To reduce the threat to their fathering, the fathers applied real and quasi-compensatory occupational adaptations. The former contributed to feelings of satisfaction and well-being but were under-valued by society. The latter adaptive occupations alienated them and contributed to further social isolation and prevented them from applying social-agency to access the next adaptive context (community and working contexts) that was necessary to their continued occupational adaptation. Proxy occupations were required to be performed by others to empower the fathers to access the necessary adaptive systems and to make these systems conducive to occupational adaptation for them. Accessing other important adaptive systems would enable them to become their idealized fathers. This goal was congruent with the values of a just society that enabled all its members to attain self-realization.

## **6.2 The findings of the study have the following implications:-**

### **6.2.1 For fathers living with HIV/AIDS**

For them occupational adaptation was compromised by:

- Prolonged engagement in quasi-compensatory /unauthentic fathering occupations which may contribute to occupational alienation promoting ill-health and non-well-being
- The experience of disempowerment to engage with necessary resources and adaptive contexts which was overriding and constrained their development and occupational adaptation
- Society that allocated the breadwinning function to fathers whether they were ill or poor. However, society failed these fathers by not providing financial buffers when a father living in poverty became ill. Negative societal attitudes and unsupportive legislation coerced the ill father into the traditional role of breadwinner regardless of his capacity to work.
- By overvaluing the breadwinning function, society prevented the expansion of the fathering role. This inhibited the development of their adaptive capacity by engagement with other occupations of fathering.

- The father with HIV/AIDS' capacity for occupational adaptation was arrested within the second level of the development of creative ability, that of self-differentiation. An unresponsive occupational context prevented further self-directed occupational adaptation.
- The father living with HIV/AIDS who is dependant on another person acting in proxy to facilitate access to another adaptive system and therefore to promote their continued occupational adaptation independently.

### **6.2.2 For Occupational Science:**

- Further research is needed to establish the foundation of core and generic adaptive occupations within human occupation and occupational adaptation

### **6.2.3 For Occupational Therapy**

- It is suggested that the applied Model of Creative Ability could be used to understand the stages and contexts of occupational adaptation and these could inform research and practice
- It would be useful to establish the adaptive systems pertaining to specific communities: this would serve to inform the occupational therapist of the specific points of intervention.

- The findings have shown that the fathers sub-consciously engaged in occupational adaptation. Therefore they tended to utilize a course of occupational adaptation as they know it. Making this known to clientele would be an important intervention focus for occupational therapy. This may include interventions of counselling and awareness-creation.
- Developing practice to include a client-centred and partnership approach will serve to empower the client and to engender self-directedness.
- Occupational therapy has a vital role to play in influencing the institutions that determine the availability, value and reward of fathering occupations
- Occupational therapy by applying proxy occupations can reduce barriers to occupational health and create health-promoting contexts for occupational adaptation
- Therapeutic techniques of counselling and meaning-creation can facilitate growth and occupational adaptation for the father living with HIV/AIDS
- Group sharing is self-reinforcing and experienced as supportive and acknowledging. Creating opportunities for this practice is necessary.

#### **6.2.4 For policy makers**

- A recognition of the rights of ill persons particularly persons with HIV/AIDS, to equal living opportunities for example, subsidized and accessible health-care and working opportunities or financial alternatives.
- A recognition of the high risk for occupational disorders and ill-health for persons living in poverty because their choices and resources for occupational adaptation are so limited.
- A recognition of the internal changing role of the father while there is no outer or etic recognition of this. These expanded fathering occupations are unrecognized by society and are unrewarded.
- Working alternatives need to be created so that persons living with illnesses can remain productive as long as possible and sustain their living. Alternatively, in a developing country with more than half the population living in poverty, a country may be morally obligated to provide free social and medical assistance.
- Fathers living with HIV/AIDS expressed the need to share their experiences with others. This potential resource can be harnessed to create suitable work for them and to assist the communities in providing psycho-education and support.

In conclusion, this study has described the fragile and dichotomous conditions of living for fathers with HIV/AIDS. The emerging identity of the father as an occupational being is dependant on others performing proxy occupations to facilitate their occupational adaptation towards their life-goal of self-fulfillment. The findings indicate that these fathers are at risk for experiencing occupational alienation because of the prolonged use of quasi-compensatory occupational adaptations that threaten their authentic selves.

The biggest challenge to occupational therapists here is to care enough to make a difference – the challenge is not to remain complacent in facing a frail humanity and to uphold the right to dignified living for the fathers living with HIV/AIDS. This means that occupational therapists need to activate occupational justice within our South African society.

**APPENDIX A**

**CONSENT FORM**

**A study to describe what it is like to be a father living with HIV/AIDS and how this affects the occupations of fathering.**

If you agree to participate, **you will be asked to:**

- Share your experience of being a father living with HIV/AIDS
- Be available to participate in two individual interviews of forty-five minutes each and one group interview of forty five minutes. These will take place over a period of eight to twelve weeks.

I .....**agree to participate in this research project under the following conditions:**

- No mention will be made of my name, or any other identifying information when the findings of the study are reported
- The interviews may be tape recorded so that nothing is missed and that my words are not changed or misunderstood
- I am allowed to withdraw from the study if I wish to
- I have the right to review the transcripts of the interviews (during the second interview) and will be allowed to suggest changes for clarity or accuracy.

**Signature of the participant..... Date:../.../ 2001**

**Signature of the researcher.....Date../.../ 2001**

**Organization.....**

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