CHAPTER 3

THEORETICAL FRAMEWORK

3.1.   INTRODUCTION

This chapter serves as the theoretical foundation upon which this study was based, and includes relevant and related theories and models. In providing a theoretical foundation and understanding to some of the central concepts related to Home Based Care, as well as the role and work of home-based caregivers in general, it is hoped that a more in-depth analysis will be discerned. In particular, the theories and models to be encompassed and discussed include: Theoretical Perspectives on Basic Counselling skills; HIV/AIDS Counselling; Bereavement Counselling (which includes a discussion of attachment theory, normal grief, Kübler-Ross's five stages, Worden's tasks of mourning, and AIDS bereavement); Palliative Care, Theoretical Perspectives on Stress and Burnout; Secondary Trauma; and the Theory of Work Motivation. These theories have been chosen in particular as it is felt that they relate to and add substance to an understanding of the aims of the current research, particularly the emotional and psychological issues.

3.2.   THEORETICAL PERSPECTIVES ON BASIC COUNSELLING SKILLS

3.2.1. Defining Counselling

Like several other relatively new professions, counselling has no agreed upon body of theory. Instead, counselling can be seen to be what the philosopher Thomas Khun (1962, as cited Silverman, 1997, p. 7) called a "pre-paradigmatic" state, in which "several models (or paradigms) compete for authority". The variety of theories however that do underlie counselling include:

- *Behaviouralism* and *Cognitive Behaviour Therapy*, which involve "restructuring behaviour so as to manage problems" (Silverman, 1997, p. 6).
- *Humanistic Therapies*, which "stress empathy and person-centredness" (Silverman, 1997, p. 6)

- *Systemic Therapies*, which attempt to "locate troubles within social systems and use theoretically defined, non-humanistic techniques (e.g, circular questioning) to help to develop patients' skills at resolving such troubles" (Silverman, 1997, p. 6).

- *Psychodynamic Therapy*, which focuses on intrapsychic conflict and pain, and is individually orientated, placing an emphasis history and childhood neurosis.

In more general terms, counselling can be aptly defined as "the skilled and principled use of relationships which develop self-knowledge, emotional acceptance and growth, and personal resources". It may be concerned with "addressing and resolving specific problems, making decisions, coping with cries, working through feelings and inner conflicts, or improving relationships with others". The counsellor's role is to "facilitate the patient's work in ways that respect the patient's values, personal resources, and capacity for self-determination" (British Association for Counselling, Bond, 1990, p. 5, as cited in Silverman, 1997, p. 12). According to Knott (2003, p. 51) counselling is a "structured conversation" and not a "social conversation". It is facilitative and not prescriptive. It is a process which goes beyond simply giving prescriptive information, facilitating rather the process in which individuals are able to make their own decisions, giving them confidence to put their decisions into practice (Brems, 2001; Montgomery, 1993).

3.2.2. The Counselling Process

Despite this evident "pre-paradigmatic" state of counselling models and theory, Knott (2003) and van Dyk (2001) stress that there are generally four generic phases to most therapeutic models. Furthermore, these models can be seen to serve as practical and basic guidelines in contexts such as Home Based Care programmes where counselling is administered on very ad hoc and basic level by community caregivers. The four phases are identified as encompassing the following:

- *Defining the Relationship*

  In this phase the counsellor must clarify the counselling relationship in terms of its objectives, process and parameters (van Dyk, 2001; Brems, 2001)

- *Information Gathering*

  In this phase the counsellor spends a considerable amount of time obtaining information about the patient's current and preferred scenario so that both the

counsellor and patient have a clear understanding of the problems and then can begin planning possible intervention strategies (van Dyk, 2001).

- *Problem Description*

    Once the counsellor has dealt with the information-gathering phase, s/he needs to articulate his or her understanding of the problem dynamic based on the information provided (Brems, 2001).

- *Making Interventions*

    This phase focuses on moving away from the identification and description of problems to setting goals which are aimed at resolving the problem, deciding on methods of achieving these goals, and monitoring and evaluating the results. Intervention is not a solution, it is a process in which the patient is directly involved (van Dyk, 2001).

In practice these phases are not clear-cut and often overlap and interact with one another (McLoed, 2003; Weiner, 1998). They serve more to guide the counsellor, providing a framework that may be helpful in keeping the counsellor on track in terms of the counselling process (Brems, 2001; van Dyk, 2001; Weiner, 1998).

3.2.3. Values Underlying the Counselling Process

A counsellor's values and attitudes play a vital role within the helping process. According to the literature, counsellors should enter the helping process with "sincere respect for their patients, an open and genuine attitude, and the intention of helping their patients to empower themselves and take responsibility for their own lives" (Knott, 2003, p. 56). Thus important identified values include:

- *Respect*

    An attitude that indicates a belief that every individual is worthy, and competent to decide what s/he wants from life

- *Genuineness and Congruence*

    A congruent counsellor is honest and transparent in the counselling process and given into all roles and facades. A genuine, congruent counsellor demonstrates sincerity, honesty, clarity and so forth.

- *Empowerment and Self-Responsibility*

To achieve this value counsellors need to believe in their patient's pursuit of growth, self-actualization and self-determination, ability to change, and refrain form rescuing their patients

· *Confidentiality*

The non-disclosure of any information pertaining to a patient without that patient's informed consent

3.3.   HIV/AIDS COUNSELLING

3.3.1   Aims of HIV Counselling

According to Sims and Moss (1991, p. 77), under these circumstances counselling should entail the "facilitation of a personal understanding of, adjustment to, and acceptance of the disease and its effect upon their lives, by the patients, the people important to them, and those caring for them". Two general aims of HIV counselling include:

1. The prevention of HIV transmission
2. The support of those affected directly and indirectly by HIV.

Incorporating these two aims, prevention and support, into any model of counselling is vitally important because the spread of HIV can be prevented by changes in behaviour (Knott, 2003).

According to Silverman (1997, p. 7) and Knott (2003, p. 64), the aims of any HIV programme should include the following:
· Provide a supportive environment
· Help patients manage problems and issues
· Explore coping skills they have used before and develop new ones
· Empower patients to become self-sufficient in dealing with emerging issues and problems
· Identify and clarify people's concerns and their risk for HIV infection
· Counsel HIV- negative patients so that they know how to remain negative
· Counsel HIV-positive patients on how to avoid cross-infection and how to prevent infecting others

- Explore options with the patient that will help her or him to bring about necessary changes in behaviour. These options may include abstinence, monogamy (mutual faithfulness), and the correct use of condoms.
- Check patients understanding of how HIV is transmitted, how transmission can be prevented, and the meaning of the antibody test results
- Provide patients with information about the personal, medical, social, psychological and legal implications of being diagnosed either HIV positive or HIV negative
- To help prepare people for difficulties they may face in the future and to provide support for them, their family and their contacts.

These aims may be covered in either the pre-test and post-test counselling phases of diagnosis, or both phases, or they may be elaborated on in longer-term counselling and support programmes. Thus HIV/AIDS counselling may be long-term or short-term, depending upon the resources available and the presented needs and concerns of both the patient and his or her family. However, in South Africa it is most likely that any sort of intervention is short term due to limited resources (Knott, 2003; Russel & Schneider, 2000).

Finally, within this process it is vitally important to ensure confidentiality when counselling the patient. This is important because of the stigma attached to the HIV virus and patient's fears of disclosing (Knott, 2003; Brems, 2001). It is also important to ensure that the patient has been fully informed and therefore consented to having an HIV test. According to the Health Professions Council of South Africa and the South African Medical Association (as cited in Knott, 2003), this is recommended because an HIV test interferes with a person's rights to freedom and security of person and privacy.

3.4.   BEREAVEMENT COUNSELLING

Van Dyk (2001) and Knott (2003) urge that within settings such as Home Based Care programmes, where a majority of the patients that are seen are either infected or affected by the HIV/AIDS virus, or some other terminal illness such as cancer, counselling should be available at all stages of the illness, from pre-test counselling to bereavement support (continuum of care).

The bereavement experienced by an individual who has lost a loved one and the bereavement experienced by a terminally-ill or dying patient are both very similar. Both experience a terrible sense of loss (Kirschling, 1989; Knott, 2003). In HIV/AIDS related bereavement counselling the counselor is therefore confronted with a dual process of bereavement, namely, counselling the HIV-infected person and dealing with anticipatory grief and loss, as well as the bereavement of significant others left behind once the patient has died. In the case of lengthy terminal illnesses such as HIV/AIDS, the process of bereavement begins for the terminally ill patient with the loss of some or all of the features of someone with a normal healthy life, such as health, sex, relationships, family, energy and so forth. (van Dyk, 2001). The HIV-infected patient often suffers from psychosocial, spiritual, and social-economic experiences and needs (Knott, 2003). Significant others similarly also begin the bereavement process as they are faced with their loved ones gradual decline and loss of an active human existence. Thus, the counselling process should intervene and begin as early as possible. This will better equip and enable both the terminal patient and his or her significant others in coping with the emotional turmoil and loss associated with death (van Dyk, 2001).

3.4.1. Attachment Theory

Bowlby's theory of attachment is useful in terms of understanding and comprehending the impact of loss and the human behaviour associated with it (Knott, 2003; van Dyk ,2003). According to Bowlby (1969, as cited in Sadock & Sadock, 2003), attachments in human beings do not only develop in order to have certain biological drives and impulses met, but also to fulfill our needs for security and safety. These attachments develop in early life and are directed towards a few specific individuals, and tend to exist throughout much of the life cycle (Bowlby, 1977, as cited in Knott, 2003; van Dyk, 2001). Hence, the goal of attachment behaviour is to maintain this affectionate bond.

Situations that endanger this bond may give rise to certain specific reactions (Knott, 2003) According to Worden (1991), bereavement may be one of these specific reactions, prompted essentially by the sense of loss that occurs when one loses something or someone to which s/he is attached. Furthermore, separation or loss is seen to initiate a process of grief. Grief is seen as a very basic (and often automatic and instinctive) "biological reaction to loss that causes aggressive behaviour and stimulates attempts to regain the lost object" (Bowlby, 1997,

as cited in van Dyk, 2001, p. 292, 2001), and the extent of grief also depends greatly on the nature of the attachment, and how attached the individual was to the lost object.

3.4.2. Normal Grief

Bereavement, or a state of grieving that accompanies a loss, is "not an illness, it is a natural, healthy response". It can affect a person "socially, emotionally, spiritually, physically and behaviourally, and can produce both positive and negative states" (Knott, 2003, p. 73). According to much of the theory, however, there are often several identified *stages*, as identified by Elizabeth Kübler-Ross (1989, as cited in Knott, 2003), or *tasks*, as identified by Worden (1991), which formulate much of what is viewed to constitute "normal grief".

i) Kübler-Ross: Adjustment to the Prospect of Death- The Five Stages
According to Kübler-Ross (1989, as cited in Knott, 2003) patients go through five stages when approaching death and dying. These stages are denial and isolation, anger, bargaining, depression, and acceptance (Knott, 2003; van Dyk, 2001; Poss, 1981). She also suggested that these stages are experienced by bereaved individuals themselves.

Kübler-Ross (1972, as cited in Poss, 1981) furthermore hypothesized that each stage may vary in duration, recur, or overlap as ambivalence depending on whether that emotion has been thoroughly worked through and integrated, or not (Poss, 1981). Thus, her stages should not be seen as linear, or as a step-by-step guide to the experience of death and dying or bereavement.

The First Response: Denial
The denial stage to death or dying or to the experience of bereavement is a temporary response. It is a healthy initial reaction to any uncomfortable and, or painful experience, and allows the patient or bereaved loved one, time to mobilize other more "adaptive strategies" (Poss, 1981, p. 13). Isolation may also be a facet of the denial stage, in which the individual retreats into him/herself for a period, in order to "mobilize his/ her resources and to start coping with the situation" (Poss, 1981, p. 14). Preferably, denial slowly gives way to defenses that allow the patient to confront the situation, instead of forcing them to avoid the difficulty.

The Second Response: Anger

Anger is a common feeling often experienced by patients facing death, as well as by those who have experienced death, or the loss of a loved one. The patient or bereaved individual struggles to answer questions such as "Why?", "Why me?" or "Why now?", and may feel envious and resentful towards others who have not experienced a loss (Poss, 1981, Knott, 2003, van Dyk, 2001).

The third Response: Bargaining

In the bargaining stage the patient or bereaved individual starts to conditionally accept the his or her loss. Often this contract of bargaining is set up between the patient and the treatment team, or God (Poss, 1981).

The Fourth Response: Depression

Depression is usually the last stage through which most patients and bereaved individuals pass through before reaching an acceptance of their death, or their loss of a loved one (Poss, 1981). In this stage is a sense of loss, with which depression is usually associated, replaces feelings of denial, disbelief, rage and bargaining. This stage is often essential in terms of the patient or bereave individual obtaining acceptance (Poss, 1981).

The Fifth Response: Acceptance

The reality of the individual's circumstances has been obtained in this stage. It is an "experience of completion, achievement or preparedness" for what lies beyond or ahead (Poss, 1981, p. 19). It is not happiness, but a preparedness.

ii) Worden: The Tasks of Mourning

According to Worden (1993), once the terminally ill family member has passed away manifestations of normal grief may present themselves. These include feelings of "sadness, anger, guilt and self-approach, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief and numbness" (Worden, 1993, p. 22). He located these feelings within four tasks of mourning. Worden's theory focuses essentially on the bereaved individual and not the patient.

Task 1: To Accept the Reality of the Loss

In this task the bereaved individual is required to come to "face to face" with the reality that the person is dead, and will not return (Knott, 2003; van Dyk 2001). Worden also includes in this task the issue of denial, as expressed by Kübler-Ross. He hypothesizes that this denial may be a means of protecting oneself against the pain of loss (Knott, 2003).

Task 2: To Work Through the Pain of Grief

Various theorists in grief and bereavement stress the importance of "working through the pain of grief" (Knott, 2003, p. 75). This pain may be physical, emotional, or behavioural (Worden, 1991). According to Bowlby (1977, as cited in Knott, 2003), avoidance of conscious grieving will ultimately result in breakdown, often with some form of depression.

Task 3: To Adjust to the Environment from which the Deceased is Missing

Adjusting to the environment from which the deceased person is missing may mean different things to different people, depending on the relationship with the deceased person and his/her role in the individual's life (Worden, 1991). This may result in the experience of a degree of resentment being experienced by the individual as s/he adapts to new roles, skills and circumstances (Knott, 2003).

Task 4: To Emotionally Relocate the Deceased and Move on with Life

In this task the bereaved individual is required to find an "appropriate place for the dead in their emotional lives- a place that will enable them to go on living effectively in the world" (Knott, 2003, p. 75).

3.4.3. AIDS Bereavement

The bereavement process for AIDS-related deaths is complicated by several issues in addition to those commonly raised in normal grief (Knott, 2003). Whilst AIDS bereavement can, and often does, follow the stages or task of normal grief, these complicating issues can increase the possibility of complicated bereavement. These differentiating factors may include issues such as: the stigma associated with HIV/AIDS; homophobia and the isolation of these populations; multiple loss of friends and family members to HIV/AIDS; increased suicidal

ideation statistics associated with HIV; and increased alcohol and substance abuse associated with HIV/AIDS-affected populations (Knott, 2003).

3.5.   PALLIATIVE CARE

Palliative (or terminal) care is "active, compassionate and comprehensive care that comforts and supports individuals and families who are living with a life-threatening illness" such as HIV/AIDS or cancer (Van Dyk, 2001, p. 397). Thus it is aimed at both the those facing death and dying, as well as the family and friends of the patient. The primary purpose of palliative care is to attend to and meet the physical, psychological, social, and spiritual needs of the individual and family whilst taking in to account and being sensitive to their own personal values, belief and practices (e.g, cultural, religious) (van Dyk, 2003). It attempts to focus on the person as a "whole" (Davy & Ellis 2000).

Palliative care is coordinated and delivered by the multi-disciplinary team, which incorporates the patient, the family, the caregivers (Home-Based Caregivers), and other health and social service providers (van Dyk, 2001). Care may include medical nursing, social and emotional support, counselling and spiritual care (Davy & Ellis 2000). The essential aims and purposes of palliative care include:

- Affirming the right of the patient and the family to participate in informed discussions and make treatment decisions
- Affirming life while regarding death as a normal process
- Providing relief from pain and other distressing symptoms
- Integrate the psychological and the spiritual aspects of care
- Providing a support system to help both patient and family
- Helping the patient to die in comfort, with dignity and in keeping with their expressed wishes

Palliative care usually commences when there is no plausible chance of improvement, when treatment is no longer being effective, when the side effects outweigh the benefits, when AIDS patients no longer wish to continue with treatment, when a child's condition becomes unbearable, and or when the body's vital organs begin to fail (O'Brien & Monroe, 1990; van

Dyk, 2001). Palliative care also encourages allowance for the patient to choose where s/he would like to die. This may be at home, at a hospice, or a terminal care facility (Davy & Ellis 2000; Sims & Moss, 1995). The support of the local community is also often mobilized, especially by hospices adopting palliative care. This is encouraged in order to help the caregivers (usually the women in the family) to cope with the caring for and dying of the patient.

3.6.   THEORETICAL PERSPECTIVES ON STRESS AND BURNOUT

3.6.1.   Burnout and Stress Defined

The term burnout comes from the psychiatric concept of patients who were burned out physically, emotionally, spiritually, interpersonally, and behaviourally to the point of exhaustion (Maslach, 1982). It was a term first coined in the 1970s by Herbert Freudenberger, who used the term to describe young, idealistic volunteers who were working with him in alternative health care settings and who started to look and act worse than many of their patients (Maslach, 1982, Muldary, 1983)

Burnout is conceptualized as a particular type of stress occurring primarily in professional contexts where work demands, especially those of an interpersonal nature, lead to chronic emotional exhaustion, depersonalization and a reduced sense of personal accomplishment (Cordes & Dougherty, 1993). It is an internal psychological experience involving feelings, attitudes, motives and expectations (Gueritault-Chalvin, Kalichman, Demi & Peterson, 2000). It is a syndrome of "excessive emotional and physical strain" and exhaustion which presents itself when "the necessary care and support" being provided to Health Care Professionals and or Home-Based Caregivers is inadequate or absent (WHO, 2002, p. 42).

3.6.2.   Burnout and Stress in HIV/AIDS Health Professionals and Home-Based Caregivers

According to van Dyk, (2001), Ross, Greenford & Bennett (1999), Lopez-Castillo, Gurpegui, Ayuso-Mateos, Luna and Catalan, Gurpegui, Ayuso-Mateos, Luna and Catalan (1999) there is nothing more stressful and draining on health care professionals' and Home-Based

Caregivers' resources than caring for, and or counselling patients with HIV/ AIDS. The proposed reasons for this are that Health Care Professionals and Home-Based Caregivers, as well as patients themselves, are faced with dreadful existential issues such as the vulnerability of youth, continuous physical and psychological deterioration, their own mortality, stigma, and the fear of contagion and death (van Dyk, 2001; Lopez-Castillo, Gurpegui, Ayuso-Mateos, Luna and Catalan et al 1999).

3.6.3. Stress and Burnout: Manifested Symptoms

According to the literature (Helen Joseph Hospital Psychology Department, 2002; Gueritault-Chalvin et al, 2000; Montgomery, 1993; Muldary, 1983; Maslach, 1982; Ross, Greenford & Bennett, 1999; van Dyk, 2001; WHO, 2002) burnout it a multidimensional phenomenon, consisting of behavioural, physical, interpersonal, and attitudinal components.

i) Behavioural Symptoms
Behavioural symptoms of stress and burnout result in direct changes in observable behaviour, and may include some of the following:
- Reduced quantity and or efficiency of work
- Use and abuse of alcohol and illicit drugs
- The development of a negative attitude towards ones job i.e, a general loss of interest in and commitment to work and a lack of job satisfaction, as well as a marked increase absenteeism
- A decision to leave the job or profession
- Increase in risk taking
- Complaining
- Changing or quitting one's job
- Loss of enjoyment
- Vacillation between extremes of over involvement and detachment
- Change in or cessation of religious affiliation
- Suicide attempts

ii) Physical Symptoms

Physical symptoms manifest as a direct response to the body's response to stress and burnout, and may include several of the following symptoms:

- Chronic Fatigue
- Lower resistance to infectious illness and disease
- Migraines
- Poor coordination
- Ulcers
- Insomnia or hypersomnia
- Gastrointestinal disorders
- Muscular tension
- Increase or decrease in appetite
- High blood pressure

iii) Interpersonal Symptoms

Stress and burnout may result in marked changes in an individuals interpersonal relationships. Examples of this may include:

- Withdrawal from family, friends and colleagues
- Feeling drawn to people who are less secure
- Breaking up of long-lasting relationships
- No separation of professional and social life
- Allowing patients to abuse the privacy of one's home, by calling or visiting at any time
- Loneliness
- Loss of ability to relate to one's patients
- Avoidance of close interpersonal contact
- Inability to cope with minor interpersonal problems

iv) Attitudinal Symptoms

Attitudinal symptoms may include symptoms such as:

- Irritability, tension, tearfulness, loss of concentration, sleeplessness, chronic exhaustion, depression, feelings of emptiness, and or feelings of anxiety or distress

- The development of a negative self-concept, loss of confidence and a diminished self-esteem
- Cynicism
- Paranoia
- Boredom
- Guilt
- Rapid mood swings
- Hopelessness
- Entrapment in job and relations
- Hypercritical attitude toward institution and colleagues

3.6.4. The Aetiology of Stress and Burnout

Much of the stress experienced by Home-Based Caregivers is inherent in the very nature of the work they do i.e. dealing with an incurable and extremely cruel disease that knows no boundaries in terms of age, race, class or gender, and which causes terrible suffering. According to UNAIDS (2000a) and much of the theory relating to burnout (Gilliland & James, 1993; Montgomery, 1993; Muldary, 1983; Maslach, 1982; Ross, Greenford & Bennett, 1999; van Dyk, p. 283, 2001; WHO, 2002), burnout can be caused by several contributing factors: financial hardship; the stigma associated with HIV/AIDS; secrecy and fear of disclosure among people with AIDS; over-involvement with people with AIDS and their families; personal identification with the suffering of people with AIDS; difficult patients; terrible plight of children, workloads; and frustration.

i) Financial Hardship

AIDS in Africa, particularly, is most often concentrated among the very poor. Furthermore, it is often the case that the Home-Based Caregivers themselves are faced with the same issues of poverty that their patients face, volunteering their time (Knott, 2003; van Dyk, 2001). This results in many Home-Based Caregivers baring an enormous financial burden, often only receiving a small stipend or incentive from a local NGO, Department of Health, FBO or CBO.

ii) The Stigma Associated with HIV/AIDS

HIV/AIDS stigmatizes both infected and uninfected individuals working in the field. This 'secondary stigma' can have a detrimental effect on the Home-Based Caregivers status with his or her family, friends and the community, and can deprive him or her of the very support s/he needs (UNAIDS, 2002a).

iii) Secrecy and Fear of Disclosure Among People Living with AIDS

Secrecy and fear of disclosure among people with AIDS can make the task of caring for AIDS patients very difficult. For example Home-Based Caregivers often find it difficult to pass on knowledge or health care skills to family members. This is especially difficult in instances were family members may be completely unaware of their relatives' status. Furthermore, if the family is unaware or refuses to accept their relatives' status it is difficult for Home-Based Caregivers to prepare and educate the family on health matters, and even prepare them for the eventual death of their loved one (van Dyk, 2001; Montgomery, 1993; Muldary, 1983).

iv) Over-Involvement with People Living with AIDS and Their Families

Home-Based Caregivers often experience stress because they are unable to meet all of their patients needs all of the time. This may result in feelings of inadequacy and guilt. They may also feel immense loss or sadness after the death of a patient and even feel responsible for not preventing their death to some extent (van Dyk, 2001).

v) Personal Identification with the Suffering of People with AIDS

Because many caregivers are HIV-infected themselves whilst caring for their patients, they witness how they too may suffer and die themselves one day (UNAIDS, 2002a; van Dyk, 2001). This can be both extremely stressful and traumatic.

vi) Difficult Patients

HIV/AIDS patients often are very needy, both physically and emotionally, and can be difficult patients to manage in general (van Dyk, 2001).

vii) Terrible Plight of Children

It is very difficult for Home-Based Caregivers to manage and deal with any children left behind (orphans) by deceased parents. Often it is difficult for Home-Based Caregivers to maintain their boundaries in such instances. Feelings of helplessness are common.

viii) Workloads

The workload in this field of work is often very demanding, and Home-Based Caregivers frequently experience stress due to the lack of space and privacy in their work (van Dyk, 2001). Working *in* the community means that they often never stop working, constantly being referred new patients, counselling and or advising patients, family and friends (Knott, 2003; Russel & Schneider, 2000).

ix) Frustration

Volunteer Home-Based Caregivers especially, but also other health care professionals, experience immense frustration because of the very nature of their work. For example Home-Based Caregivers often report not feeling supported by their superiors, the feel that they work in isolation from one another, they do not have a voice in decision-making processes, they have little autonomy, they lack the necessary supportive infrastructures, supervision is often absent or kept to a minimum, and required referral mechanisms are not always in place (van Dyk, 2001).

Burnout is thus a syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment (Maslach, 1982). It is not a sudden syndrome or symptom but rather its path of erosion is slow and often unconscious. It is not the result of a sudden crisis. Rather it is the result of months or years of slow and gradual erosion of one's resources.

3.6.5. Levels of Burnout

Burnout can be categorized as occurring at one of three levels; trait, state and activity (Gilliland & James, 1993). At a trait level, it is all-pervasive, affecting every aspect of the health professional or health workers life. The health care professional or health worker becomes completely dysfunctional (Gilliland & James, 1993). At the state level, burnout is periodic or situational, and may therefore not result in complete dysfunction of the individual

(Gilliland & James, 1993). Finally, burnout may also be activity based. This occurs when an activity is performed repeatedly at an intense level, eventually wearing the health care professional or health worker down.

3.6.6. Stages of Burnout

Similar to the levels of burnout, another way of characterizing burnout is in stages (Edelwich & Brodsky, 1980; Helen Joseph Psychology Department, 2002). According to Edelsich and Brodsky (1980) four typically identified stages include: enthusiasm; stagnation; frustration and apathy.

i) Stage of enthusiasm

This is a stage of high hope, high energy, and unrealistic expectations, characteristic of when an individual enters a new job. If such idealism is not addressed in orientation and or training programmes, and the individual's expectations are not brought into alignment then the individual will invariably reach the stagnation stage of burnout (Edelwich & Brodsky, 1980).

ii) Stage of stagnation

The thrill begins to wane during this stage as the individual increasingly begins to experience his/her job as routine and stagnant. Personal, financial and career needs are no longer met. If intrinsic and extrinsic reinforcement does not occur, the individual will move into the next stage, frustration (Edelsich & Brodsky, 1980).

iii) Stage of frustration

The individual, at this stage, questions his/her job, with a feeling of unfulfilled expectations and diminishing accomplishments. S/he may start questioning the effectiveness, value and impact of his or her efforts, resulting in frustration . This frustration is in all likelihood is likely to effect other employees in the workplace (domino effect) (Edelwich & Brodsky, 1980). Possible ways of dealing with and managing such frustrations may include running workshops, establishing support groups or providing individual support to the individual concerned.

iv) Stage of Apathy

In this stage the individual is likely to develop strong feelings of personal inadequacy, which further reduces his accomplishments, leading to helplessness. Further compounding this stage are denial and little objective in terms of understanding what is happening. Intervention is mandatory at this stage if burnout is to be managed and dealt with effectively.

3.6.7. The Prevention of Burnout

Health care professionals in general, and especially Home-Based Caregivers, need to look after *themselves* and ensure that they take on some of the necessary responsibilities in terms of ensuring that they are not at risk of burnout. According to UNAIDS (2002a), one of the first ways to achieve this is for employees to acknowledge the level of stress incurred by their workers. This helps to legitimate and 'normalise' employees' feelings of stress to their experiences, shifting the blame away from the self, such as feelings of personal weakness or a lack of professionalism (van Dyk, 2001; Maslach, 1982).

According to the literature and some of the theories of burnout (Maslach, 1982; Montgomery, 1993; Muldary, 1983; Ross, Greenford & Bennett, 1999; UNAIDS, 2002a; van Dyk, 2001; WHO, 2002) the following skills may help Home-Based Caregivers to cope with the pressures of working with HIV-infected patients:

i) Re-evaluation of expectations and performance goals
Home-Based Caregivers and their employees need to be aware of what they can realistically expect from themselves and their patients

ii) Care for Oneself (Self-Care)
The Home-Based Caregiver should take responsibility for his or her own physical and mental health. Factors such as a healthy diet, exercise, rest and enough sleep are important. Home-Based Caregivers should also nurture themselves and take time out to do the things they enjoy, like walking, listening to music etc. Relaxation exercises, breathing exercise, visualization, and mediation work are also all beneficial in terms of reducing stress

iii) Using Support Systems

Home-Based Caregivers cannot cope with the tremendous burden of HIV/AIDS without support on a personal as well as organizational level. Thus Home-Based Caregivers need to create and use personal support systems (e.g, Spouse, partner) with whom they can talk. They should also be encouraged to share their experiences, and listen and talk with each other. Support Groups can be very empowering, allowing colleagues to share their concerns, problems and fears.

iv) Organizational Support

Volunteer and home-based care organizations in particular cannot afford to lose the Home-Based Caregivers who are the mainstay of care for people with AIDS. Thus it is important that caregivers, for the sake of their morale and self-confidence, receive recognition and appraisal for their work. Frequent contact between caregivers and supervisors is important. Home-Based Caregivers should also be considered and included where possible in managerial decisions.

v) Knowledge is Empowering

Training plays a central role in the management of stress and burnout amongst Home-Based Caregivers (van Dyk, 2000). Home-Based Caregivers should be informed and equipped with the skills and practical tools to cope with stress and burnout e.g, relaxation exercises.

vi) Working in a Team

Working in a multidisciplinary team is an effective way of protecting staff from undue stress because it equalizes the burden of care and responsibility.

vii) Expression of Grief

The most difficult time for Home-Based Caregivers is usually when their patients dies, evoking a sense of personal loss. Thus, it is important for Home-Based Caregivers to be able to grieve their loss without shame. Home-Based Caregivers should be encouraged to use their own mechanisms and rituals in dealing with death.

Thus, it is apparent that if Health Care Professionals and Home-Based Caregivers do not learn or know how to care for *themselves*, they will run the risk themselves, of not surviving the onslaught of the HIV/AIDS pandemic.

3.7.   SECONDARY TRAUMA

The term "secondary trauma" is a relatively recent term that has emerged amongst health workers and professionals working within the helping profession (Hesse, 2002). Secondary Trauma is refers to the emotional and psychological effects as a result of working with traumatized patients (Hesse, 2002). According to Figley (1993, p. 7), secondary traumatic stress is the "natural consequent behaviours and emotions resulting from knowing about a traumatizing event experienced by a significant other-the stress resulting from helping or wanting to help the traumatized or suffering person". Another commonly used term used to describe this experience is "compassion fatigue" (Figley, 1993).

Pearlman and Saakvitne (1995) comment that long-term empathic engagement with traumatized patients can transform a health workers way of experiencing the self, others, and the world. Furthermore, many researchers urge that secondary trauma should not be confused with burnout (Hesse, 2002). Whilst health workers may experience burnout and or high levels of stress, secondary trauma differs from burnout in that it specifically involves exposure to emotionally trying images and descriptions of suffering (Hesse, 2002). It involves patterns of re-experiencing patients' trauma, avoidance, and numbing, and persistent arousal, and differs to burnout in that it is not necessarily gradual and or accompanied by emotional exhaustion. Secondary trauma can emerge rapidly with little warning and can cause helplessness and confusion (Figley, 1993). According to Courtois (1993, as cited in Hesse, 2002) secondary trauma may therefore overlap to some extent with burnout, but fundamentally it is a different concept.

Secondary trauma can therefore be seen have a serious impact on the health care worker and professional's well being in general. Home-based caregivers can be seen to be faced with the reality of death and the dying on a daily basis, which is not only highly traumatic, but which may also effect their perception of themselves, others and the world around them, and in turn the quality of their work (Uys, 2003).

3.8. THE THEORY OF WORK MOTIVATION

In the face of potentially experiencing emotional and psychological effects such as burnout, stress and or secondary trauma, it appears relevant to discern what motivating factors contribute to home-based caregivers and health professionals, in general, to carry on doing the work that they do.

According to Franken (1988), a major motivational factor in the work environment is money. Money obviously provides the means for a wide variety of goods and services, and also provides a sense of worth and self-esteem. However, despite money being seen as the "bottom line" among reasons that people work, it is also evident that different people earn and accept to work for a variety of amounts of money. In recent years it has been suggested that whilst remuneration for work done is important, it is by no means the only feature. Other behavioural and psychological factors are believed to exist (Franken (1988; Toates, 1986). Maslow's (1970) need-fulfillment model highlights some of these factors.

3.8.1. Maslow's Need-Fulfillment Model

Abraham Maslow's (1970, as cited in Franken, 1988) theory of human motivation is the most renowned of the need-fulfillment theories. According to Maslow (1970, as cited in Franken, 1988, p. 460), human beings are born with a set of needs that not only "energize but direct behaviour". Furthermore, he argues that these needs are organized in a hierarchical fashion whereby needs lowest in the hierarchy must be satisfied first. These needs dominate a person's attention until satisfied.

The first needs at the bottom of Maslow's hierarchy of needs are "physiological needs" (Franken, 1988). These pertain to the basic needs of eating, drinking, and or control in temperature in the environment, and are necessary in order to live and function normally (Franken, 1988). All other needs are thought to be secondary to these physiological needs.

Once these basic physiological needs have been met and satisfied, the next needs identified are "safety needs" (Franken, 1988). For humans, safety comes from knowing about our environment, and making it predictable and lawful.

Following this need is the need to "belong and to be loved" (Franken, 1988). Humans display a strong desire to belong, for example, being part of a group, family or even an organization.

The next need on Maslow's hierarchy of needs is the need for "esteem" (Franken, 1988). All people in society generally have a need or desire to have a good opinion of themselves (Franken, 1988). Maslow (1970, as cited in Franken, 1988, p. 462) suggests that there are "two subsidiary sets" to esteem. The first pertains to the desire for strength, achievement, adequacy, mastery, and competence. The second relates to the need for reputation and prestige, status, recognition, dignity and or appreciation. Satisfaction of the esteem needs results in feelings of self-confidence, worth, strength, and capacity.

Finally, the last need on Maslow's hierarchy of needs is the need for "self-actualization" (Franken, 1988). This relates to the identification of a person's unique skills and abilities. This sense of uniqueness provides an experience of satisfaction for the individual.

3.9.   CONCLUSION

This chapter has covered the theoretical foundations for the study. It has explained and discussed the relevance of various theories and theoretical models for the present study, including that of basic counselling skills, HIV/AIDS counselling, bereavement, palliative care, secondary trauma and work motivation.