

**STRESS, COPING, AND THE ROLE OF SOCIAL SUPPORT IN
LIVING WITH HIV/AIDS: A LITERATURE REVIEW**

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STATEMENT

I, the undersigned, hereby declare that the work contained in this assignment is my own original work, and that I have not previously in its entirety or in part submitted it at any university for a degree.

Signature

Date

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ABSTRACT

HIV/AIDS places much stress on those living with the disease. An understanding of the processes of stress and coping and how these relate to people living with HIV/AIDS (PLWHA) can inform the nature of services we offer to PLWHAs. Social support has been shown to play a mediatory role in the stress response and is also considered to be a problem-focused coping strategy. This paper presents an overview of the literature on stress, coping and social support with the aim of assisting healthcare workers to understand how these issues relate to HIV/AIDS and to show how healthcare workers, and, specifically psychologists can use their unique competencies and skills to enhance the quality of life of PLWHAs.

SPANNING, HANTERING EN DIE ROL VAN SOSIALE ONDERSTEUNING IN DIE SAAMLEEF MET MIV/VIGS: 'n LITERATUUR OORSIG

OPSOMMING

MIV/VIGS plaas baie druk op mense wat met die siekte moet saamleef. Insig rakende die prosesse van spanning en hantering daarvan en hoe dit verband hou met mense wat met MIV/VIGS moet saamleef, het die potensiaal om die aard van die dienste wat aan die spesifieke populasie gelewer word, in te lig. Sosiale ondersteuning blyk 'n bemiddelende rol te speel in spanningsresponse en word ook beskou as 'n probleem-gefokusde hanteringsmeganisme. Die betrokke werkstuk bied 'n oorsig van die literatuur rakende spanning, hantering en sosiale ondersteuning. Dit is gefokus daarop om bystand te verleen aan gesondheidsorg werkers om hulle insig te gee hoe hierdie kwessies met MIV/VIGS verband hou. Dit poog ook om aan te toon hoe gesondheidsorgwerkers en spesifiek sielkundiges, hul unieke bevoegdhede en vaardighede kan benut om die wat met MIV/VIGS moet saamleef, se kwaliteit van lewe te verryk.

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INTRODUCTION

The HIV/AIDS pandemic presents many unique challenges and opportunities. It is suggested that psychologists can play an important role in terms of helping people live with the disease. The purpose of this paper is to examine the stress placed on individuals living with HIV/AIDS, to explore how individuals cope with such stress and to understand how a psychosocial resource such as social support can mediate in the stress response. Based on this theoretical understanding of stress, coping and social support, practical implications and recommendations will be presented to assist psychologists and healthcare workers in the planning of interventions to meet the psychosocial needs of people living with HIV/AIDS and ultimately to improve their quality of life.

This paper begins by looking at the scale of the HIV/AIDS epidemic globally, regionally and specifically in South Africa. By means of a literature review a theoretical framework for understanding stress, coping, psychoneuroimmunology and social support will be presented. Following this, suggestions as to how this theoretical framework relates specifically to HIV/AIDS is examined and, finally, recommendations arising from the literature review are discussed.

UNDERSTANDING THE HIV / AIDS EPIDEMIC

The global AIDS epidemic is one of the greatest challenges facing our generation. AIDS is a new type of global emergency – an unprecedented threat to human development requiring sustained action and commitment over the long term.

Kofi Annan, Secretary General of the United Nations (UNAIDS, 2004, p. 7)

HIV/AIDS is perhaps one of the greatest challenges that humankind has been faced with. According to the 2004 UNAIDS report on the global AIDS epidemic, there were 37,8 million people living with HIV/AIDS globally at the end of 2003. 4,8 million new HIV infections were reported in 2003 and 2,9 million people died of AIDS globally (UNAIDS, 2004). In Sub-Saharan Africa there are currently 25 million people living with HIV/AIDS. Sub-Saharan Africa is home to ten percent of the total global population but close to two thirds of all people living with HIV/AIDS are found in this region. UNAIDS (2004) reported that in 2003 there were 3 million new HIV infections in Sub-Saharan Africa. This represents 62,5 percent of the total new infections globally. It is estimated that 2,2 million people in Sub-Saharan Africa died of AIDS in 2003 representing 76 percent of the total AIDS deaths globally.

At the end of 2003 there were 5 300 000 people living with HIV/AIDS in South Africa and 370 000 people died of AIDS (UNAIDS, 2004). In South Africa the statistics on HIV prevalence are generated by surveys completed at antenatal clinics. The latest antenatal survey shows that 24,8 percent of the total South African population are living with HIV/AIDS. The province with the highest prevalence is KwaZulu-Natal where approximately 37,5 percent of the population are living with HIV/AIDS. The Western Cape is the province with the lowest prevalence of HIV infection with 13,1 percent of the population living with HIV/AIDS. The latest statistics indicate that the epidemic is slowly stabilising in South Africa and “while HIV rates have not declined nationally, the rate of increase has slowed, indicative of a mature epidemic” (Antenatal survey, 2004, p. 15).

These statistics present a picture of a disease that is slowly eroding the population of Sub-Saharan Africa. HIV/AIDS is a serious problem and “it is an exceptional disease with exceptional and wide-ranging impact; it requires an exceptional response” (UNAIDS, 2004,

p. 20). The challenge is for psychologists to be part of the exceptional response rather than being overwhelmed by the exceptionality of the disease.

The question that arises is why the spread of HIV has been so rampant in Southern Africa. UNAIDS (2004) has identified the following reasons for the rapid spread of the disease in Southern Africa: poverty, social instability resulting in family disruption, high levels of other sexually transmitted infections, low status of women, sexual violence, ineffective leadership at critical periods in the spread of HIV and high mobility linked to migratory labour systems. There are a number of similar factors that have contributed to the pattern and severity of the HIV/AIDS epidemic in South Africa. These factors include the high incidence of other sexually transmitted infections; disrupted family and communal life due to the migrant labour system; good transport infrastructure and high mobility; resistance to condom usage; the low status of women in society and social norms relating to the acceptability of high numbers of sexual partners and a reluctance to open discussion of sexual issues (ABT Associates Inc. South Africa, 2000 as cited in Gilbert & Walker, 2002). The pattern that emerges of the epidemic in South Africa is that the epidemic is mainly a heterosexual epidemic with high rates of infection in the general population and a higher percentage of women infected with the virus than men (Gilbert & Walker, 2002). The HIV/AIDS problem in South Africa is a complex one and it seems that "the mixture and complex interaction of these material, social, cultural and behavioural factors shape the nature, process and outcome of the epidemic in South Africa" (Gilbert & Walker, 2002, p. 1107).

The introduction of anti-retroviral medication will allow people with HIV/AIDS to live longer and healthier lives and will mean that AIDS will no longer be considered a short-term fatal illness but rather a chronic, long-term illness (Greene, Frey, & Derlega, 2002; Pakenham, & Rinaldis, 2002; Pierret, 2000; Sikkema, Kalichman, Hoffman, Koob, Kelly, & Heckman, 2000; Smith & Rapkin, 1995; Tsasis, 2000). An increase in the life expectancy of people living with HIV/AIDS (PLWHA) means that the quality of life of PLWHAs is going to become increasingly important and a shift is going to be required in terms of the focus of psychosocial interventions (Coetzee & Spangenberg, 2003; Gielen, McDonnell, Wu, O'Campo, & Faden, 2001; Pakenham & Rinaldis, 2002). Whilst the issues around prevention and behaviour change continue to be important, healthcare professionals need to start considering how to facilitate adjustment to living with a chronic illness and how to promote well-being (Friedland, Renwick, & McColl, 1996). An increase in life expectancy

may result in PLWHAs becoming increasingly vulnerable to multiple emotional and social problems. It is therefore crucial that ways to assist PLWHAs with the adjustment to these problems are explored (Kalichman, Sikkema, & Somlai, 1996; Tsasis, 2000).

HIV/AIDS needs to be viewed as more than a medical issue. Healthcare professionals need to understand and appreciate the complex and intricate social issues associated with the disease (Taylor, 2001). In the field of HIV/AIDS over the last few years there has been a shift from focusing on the issues of death and dying to focusing on how people are living and coping with HIV/AIDS (Coetzee & Spangenberg, 2003). It would appear that healthcare professionals need to move beyond a focus on prevention and treatment and start adopting a more holistic approach and consider how people cope with and manage HIV infection and AIDS illness (Pierret, 2000). HIV/AIDS has been described as “the ultimate biopsychosocial phenomenon” (Schider as cited in Lindegger & Wood, 1995, p. 8). It is important that healthcare professionals adopt an approach and interventions that encompass the whole person (van Dyk, 2001).

In South Africa there has been a renewed commitment to improve the mental health of the population and the provision of mental health services but it appears that the impact of HIV/AIDS on mental health has not been taken seriously (Freeman, 2004). In his article entitled “HIV/AIDS in developing countries: heading towards a mental health and consequent social disaster?” Freeman highlights the mental health implications of HIV/AIDS and explores how these will be experienced at various levels namely individuals, families, communities and society. He identifies the following groups of people within South African who will require mental health interventions due to the impact of HIV/AIDS: (1) people unsure of their HIV status, (2) people diagnosed HIV positive, (3) family and caregivers of HIV-infected people, (4) people left behind following AIDS-related deaths and (5) society’s mental health in the face of the HIV/AIDS pandemic. He makes various suggestions as to types of interventions each group needs in order to minimise the impact of HIV/AIDS on their mental health. A common thread that seems to run through his recommendations is the provision of various types of social support for the different groups. For the group people diagnosed HIV positive, who are the focus of this paper, he recommends that this group needs to be “encouraged to disclose their status through the creation of environments (within families and communities) that are *supportive and comforting*” (Freeman, 2004, p. 155). It therefore becomes clear that an understanding of

social support and the role it plays within the context of HIV/AIDS will be able to assist healthcare workers in their endeavours to provide effective interventions for PLWHAs.

As science progresses, the HIV/AIDS epidemic will continue to change its face but for the people living with HIV/AIDS the issues will remain the same. At this point in the history of HIV/AIDS scientists continue to work on the development of a vaccine but it appears that for the immediate future anti-retrovirals will provide PLWHAs with a new sense of optimism and hope. Healthcare workers have a role to play in addressing the psychosocial needs of PLWHAs in order to ensure that while people cope physically with HIV/AIDS they also have the resources to cope at an emotional and psychological level.

THEORETICAL FRAMEWORK

Stress and coping

The cognitive theory of Lazarus and Folkman underpins this paper. This theory presents a transactional, cognitive-phenomenological model of stress and coping (Folkman & Lazarus, 1985; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986b; Folkman, Lazarus, Gruen, & DeLongis, 1986a; Lazarus, 1999; Terry, 1994). The model is transactional in that it considers the person and his or her environment or context as being in a “dynamic, mutually reciprocal, bidirectional relationship” (Folkman et al., 1986a). It therefore proposes that stress is a relationship between the person and the environment or context where the person feels that there are threats to his or her well being and an environment in which the person’s resources are taxed or exceeded (Folkman & Lazarus, 1985; Folkman et al., 1986b).

In determining whether an encounter or situation is stressful or not, the individual evaluates the encounter by means of a process known as cognitive appraisal (Carver & Scheier, 1994; Folkman & Lazarus, 1985; Folkman et al., 1986a; Folkman et al., 1986b; Lazarus, 1999). By means of primary cognitive appraisal the person evaluates the meaning of the event in terms of its potential threat or harm and by means of secondary cognitive appraisal the person assess his or her coping abilities to deal the potential threat, harm or challenge of the event (Carver & Scheier, 1994; Folkman & Lazarus, 1985; Folkman et al., 1986a; Folkman et al., 1986b; Lazarus, 1999).

Coping is defined as “cognitive and behavioural efforts to manage (master, reduce, or tolerate) a troubled person-environment relationship” (Folkman & Lazarus, 1985, p. 152). The process of coping is not static but is in a constant state of flux based on how the person appraises his or her changing relationship with the environment (Folkman & Lazarus, 1985; Lazarus, 1999). Coping is considered to have two major functions namely stress reduction and management of the problem (problem-focused coping) and the regulation of the emotion accompanying the stress or problem (emotion-focused coping) (Carver & Scheier, 1994; Folkman & Lazarus, 1985; Folkman et al., 1986a; Folkman et al., 1986b; Lazarus, 1999; Terry, 1994). Problem-focused and emotion-focused coping strategies do not occur in isolation but may co-occur and in turn may even facilitate each other (Carver & Scheier, 1994).

In applying this model of stress and coping to HIV/AIDS, it is clear that the meaning a person attributes to an HIV positive diagnosis and a person's ability to access appropriate physical and emotional resources, may influence the manner in which an individual will cope with living HIV/AIDS.

Social support

Social support provides the interface between the individual and the various social systems in the individual's environment. Social support can therefore be thought of as that which "links the social and the individual" (Orford, 1992, p. 61). Thus social support concerns relationships between individuals within the social environment as well relationships between the individual and the environment. According to Schmitz and Crystal (2000) "the simplest and most powerful single measure of social support appears to be the presence of an intimate, confiding relationship" (p. 667). Within these relationships individuals are provided with resources to cope with their problems and to find sources of "coping assistance" which assist the individual's efforts to manage his or her stress (Thoits, 1986, p. 417).

For the purposes of this paper the concept of social support will be considered from a systemic point of view where social support is "best viewed as a complex process unfolding in an ecological context" (Vaux, 1990, p. 507). Social support is not a static concept but rather it reflects the complex relationships and fit between the individual and his or her environment (Shinn, Lehmann, & Wong, 1984; Vaux, 1990). Thus social support "influences individual outcomes, such as psychological distress, but in turn is influenced by stressors, distress, personal characteristics of the recipient, and the environmental conditions" (Shinn et al., 1984, p. 56).

Social support has been shown to play a direct role in the alleviation of distress and also serve as a buffer against stressful events (Cohen, 1988; Cohen & Wills, 1985; Kalichman et al., 1996; Syrotuik & D'Arcy, 1984). For the purposes of this paper both of these outcomes of social support will be considered. Social support can serve various functions depending on the nature of the stressful event and the individual concerned. This paper will focus on three types of social support namely emotional support, informational support and instrumental support as these types of social support seem to be most applicable to people living with HIV/AIDS. Emotional support consists of "affection, comforting, and encouragement that result in a sense of belonging and personal worth" (Kalichman et al.,

1996, p. 590). Emotional support has also been referred to as “esteem support, expressive support, self-esteem support, ventilation, and close support” (Cohen & Wills, 1985, p. 313). Informational support is “help in defining, understanding, and coping with problematic events” (Cohen & Wills, 1985, p. 313) and involves learning more about the particular problem and using this knowledge to find solutions to the problem (Orford, 1992; Kalichman et al., 1996). Instrumental support or tangible support is the provision of material resources and practical help (Cohen & Wills, 1985; Kalichman et al., 1996; Orford, 1992).

Psychoneuroimmunology

Psychoneuroimmunology (PNI) is concerned with the complex bi-directional interactions between various psychological factors such as emotions and behaviour, the central nervous system (CNS) and the immune system (Solomon & Temoshok, 1987; Solomon, Kemeny, & Temoshok, 1991). Psychoneuroimmunology is a multidisciplinary field of study and as such provides a framework from which to consider a HIV/AIDS from a biopsychosocial paradigm and takes into account the complexities and multifactorial nature of the disease (Ader, 2001; Solomon & Temoshok, 1987; Solomon et al., 1991).

Research suggests that negative life events or stressors result in negative affective states such as depression which in turn affect human immunity (Ader, 2001; Herbert & Cohen, 1993; Panzer & Viljoen, 2002; Solomon & Temoshok, 1987; Solomon et al., 1991). The interaction between stress and immunity is complex. One of the reasons a link has been made between stress and immunity is the fact that immune cells have receptors for the hormones that are activated during exposure to a stressful situation; thus implying that these same hormones released during times of stress play a role in immune system modulation (Herbert & Cohen, 1993). Another mechanism that links stress and immunity is the association of stress with specific behaviours that modulate immune response. For example decreased sleep, reduced physical exercise, poor diet and increased substance abuse that could arise as a result of stressful life events result in an alteration to immune responses (Herbert & Cohen, 1993). Since HIV/AIDS is a disease that directly attacks the immune system and in turn causes much psychological stress, one can see the relevance of considering the psychoneuroimmunological aspects of HIV/AIDS.

Interpersonal relationships are a further psychosocial influence on immunity (Kiecolt-Glaser & Glaser, 1988). According to Kiecolt-Glaser and Glaser (1992), “association

between personal relationships and immune function is one of the most robust PNI findings" (p. 572). Kiecolt-Glaser and Glaser (1988) provide an overview of research into the role that the quality of relationships play in immune functioning and show that interpersonal relationships do have health-related outcomes. Of particular interest in the field of HIV/AIDS is research that found that bereavement has been associated with poorer immune function (Bartrop, Luckhurst, Lazarus, Kiloh, & Penny, as cited in Kiecolt-Glaser & Glaser, 1988; Irwin, Daniels, Smith, Bloom, & Weiner, as cited in Kiecolt-Glaser & Glaser, 1988). People who live with HIV/AIDS often have connections to others with HIV/AIDS and thus could be exposed to frequent deaths in their social support network. This could increasingly weaken an already compromised immune system.

A study conducted by Leserman and colleagues with a sample of 82 HIV-infected homosexual men found that increased stress and lower levels of social support may accelerate the course of HIV disease progression to AIDS (Leserman, Jackson, Petitto, Golden, Silva, Perkins, Cai, Folds, & Evans, 1999; Leserman, Petitto, Golden, Gaynes, Hongbin, Perkins, Silva, Folds, & Evans, 2000). The participants in this study were followed up every six months over a seven and a half-year period and at each follow up their stressful life events, depressive symptoms and satisfaction with social support were assessed. The findings show that "men with more cumulative stressful life events, greater use of denial as a coping mechanism, less social support, and higher cortisol levels may be at greater risk for HIV-1 disease progression" (Leserman et al., 2000, p. 1226).

Research conducted by Ickovics and her colleagues to determine the role that depressive symptoms played in HIV-related deaths and a decline in CD4 lymphocyte counts among women with HIV found that depressive symptoms are associated with accelerated HIV progression (Ickovics, Hamburger, Vlahov, Schoenbaum, Schuman, Boland, & Moore, 2001). The study was a longitudinal cohort study over a two-year period with 765 HIV positive women participating in the research. The women were followed up at six monthly intervals and at each interval they were interviewed, underwent a physical examination and their CD4 count was assessed. The findings suggest that HIV positive women with symptoms of chronic depression were two times more likely to die compared to those without depressive symptoms. Furthermore, women with chronic symptoms of depression showed a more rapid decline in CD4 count than those without any depressive symptoms.

A study conducted by Evans and his colleagues to investigate the impact of severe life stress on HIV disease progression found that "severe life event stress is associated with an increased rate of early HIV disease progression" (Evans et al., 1997, p. 632). In this research 93 HIV positive homosexual men were followed up at six monthly intervals and received comprehensive medical, neurological, neuropsychological and psychiatric assessments. The results provided further evidence that there is a link between stress and immunity as seen in the accelerated HIV disease progression. It should be noted that in this study only severe life stress was shown to have an effect on immunity and not the day to day stressors which most people are exposed to.

These findings concur with the assertion of Kiecolt-Glaser and Glaser (1995) that "immune modulation by psychosocial stressors and/or interventions can lead to actual health changes" (p. 273). It is difficult to determine the exact way in which stress impacts the immune system but based on research findings we can see that there is a relationship between psychosocial factors and immune system functioning. According to Kiecolt-Glaser and Glaser (1992), "it is possible that interventions, such as psychotherapy, that enhance personal relationships, decrease distress, or enhance perceived self-efficacy could also have positive effects on immunity and, perhaps, health outcomes" (p. 573). Therefore psychologists should adapt and apply their knowledge in order to plan interventions that assist individuals to cope with such psychosocial factors in order to alleviate the negative impact these have on health outcomes.

THE STRESS OF LIVING WITH HIV/AIDS

Living and coping with an illness can be stressful but to live with a chronic illness places the individual in an experience which is immensely more stressful and such stress could severely tax the individual's coping mechanisms. Chronic diseases place a unique and demanding set of stressors on the individual. These stressors do not occur in isolation but can be considered as an "accumulation of stressors" (Schreurs & de Ridder, 1997, p. 91). Whereas an acute illness is likely to be transient, a chronic illness is not and "it tends to become the person's very life" (Pierret, 2000, p. 1589) and as such could overwhelm the individual's coping mechanisms. People who have a chronic illness are constantly concerned about their health and well being and such concern may be anxiety provoking and stressful.

The stress of living with a chronic illness

It is important to consider the role that stress plays in chronic illnesses. By understanding the relationship between stress and chronic illness, the healthcare professional is in a better position to understand the attitudes, behaviours and emotions required for people to adjust to living with a chronic illness and in so doing will be able to enhance the quality of life for such people (Coetzee & Spangenberg, 2003; Thompson, Nanni, & Levine, 1996). Stress could have direct physiological effects on chronic illnesses and may result in disease onset or rapid progression of the illness (Kiecolt-Glaser & Glaser, 1988; Kiecolt-Glaser & Glaser 1992; Kiecolt-Glaser & Glaser 1995; Serovich, Kimberley, Mosack, & Lewis, 2001). It follows then that if we understand the relationship between stress and chronic illness we will be able to offer people living with chronic illnesses appropriate and effective psychosocial interventions to enhance their ability to cope with the demands of living with a chronic illness.

AIDS is now considered to be a chronic illness (Greene, Frey, & Derlega, 2002; Pakenham & Rinaldis, 2002; Pierret, 2000; Sikkema, Kalichman, Hoffman, Koob, Kelly, & Heckman, 2000; Smith & Rapkin, 1995; Tsasis, 2000) and as such the stressors associated with other chronic illnesses are also experienced by people who are living with HIV/AIDS. However, according to Pierret (2000), HIV/AIDS differs from other chronic illnesses in a number of ways. Firstly, HIV/AIDS does not cover a single range of situations and medical conditions but it often encompasses multiple situations and medical conditions. Furthermore, the disease progresses through various stages but the progression between

stages differs between individuals. As a result, a fair degree of uncertainty accompanies living with HIV/AIDS.

The second way in which HIV/AIDS differs from other chronic illness is that the social discourse about HIV/AIDS illness has for the most part constructed HIV/AIDS as a deadly disease and has created the impression of hopelessness and despair. This is despite the fact that chronic illnesses represent the most prevalent form of illnesses that are treated.

Thirdly, HIV/AIDS differs from other chronic illnesses in the way that it impacts on an individual's social relationships. Living with HIV/AIDS threatens the safety and security of an individual's social relationships because of the fact that the disease is highly stigmatised and thus leaves the individual vulnerable to social isolation and discrimination. The issue of stigma is a complex one but is perhaps one of the most distressing consequences of being diagnosed HIV positive and living with HIV/AIDS. HIV/AIDS is highly stigmatised because it is associated with deviant behaviour; it is often tainted with various religious beliefs about immorality; it is perceived as contagious and threatening to the community and it is not well understood by the broader community (Alonzo & Reynolds, 1995).

As a chronic illness HIV/AIDS "represents a major life crisis with a unique set of stressors impacting on both the individual and the community" (Coetzee & Spangenberg, 2003, p. 207) and represents "multiple assaults" on the individual's sense of self as well as his or her social context (Fleishman, Sherbourne, Crystal, Collins, Marshall, Kelly, Bozzette, Shapiro, & Hays, 2000; Pakenham, Dadds, & Terry, 1996; Schmitz & Crystal, 2000). The stress associated with HIV/AIDS is multidimensional and arises from a number of sources such as physiological challenges, socioeconomic consequences, interpersonal consequences and psychological and emotional challenges (Coetzee & Spangenberg, 2003). In addition there are specific stressors that arise when one lives with HIV/AIDS. These include social isolation, multiple bereavements and rejection due to stigma (Pakenham & Rinaldis, 2002). Being diagnosed with HIV positive is in itself a major stressor however; the various sequelae of an HIV positive diagnosis present the individual with many additional stressors that may result in chronic strain (Friedland et al., 1996).

The nature of the stress associated with living with HIV/AIDS

Due to the nature of the progression of the disease various stressors arise at each stage of the disease. At the stage of initial diagnosis the shock of an HIV positive diagnosis can be a devastating blow. Immediately the individual is faced with the “prospect of increasing ill-health in the context of changed life-style, and the very real threat of death after some unknown period” (Chidwick & Borril, 1996, p. 272). An HIV positive diagnosis thrusts the individual into an existential crisis where he or she is faced with anxiety around death and dying (DeMatteo, Wells, Goldie, & King, 2002; Green & Sobo, 2000). At this stage the individual feels that there are definite threats to his or her well being and the overwhelming nature of receiving an HIV positive diagnosis results in a perception that his or her resources are about to be severely taxed. Thus we can see that an HIV positive diagnosis creates a stressful and situation for the individual because of the meaning attributed to such a diagnosis (Carver & Scheier, 1994; Folkman & Lazarus, 1985; Folkman et al., 1986a; Folkman et al., 1986b; Lazarus, 1999).

Stage two of the disease is the asymptomatic latent phase where the individual can live for varying lengths of time without displaying any signs or symptoms (van Dyk, 2001). At this stage the individual is faced with a fair amount of uncertainty as it is difficult to predict how quickly or slowly the person will move to the next stage of the disease (Chidwick & Borril, 1996). Alonzo and Reynolds (1995) characterise this stage as “living between health and illness” (p. 308). The stress experienced during this stage could arise as a result of having to conceal one’s status or the stress associated with disclosing as well as the fear of subsequent rejection due to stigmatisation.

The occurrence of physical symptoms that arise as a result of a deteriorating immune system and an increase in viral load as seen in stages three and four of the HIV/AIDS disease progression, creates increased stress for the PLWHA and represents one of the key crises in the disease (Burgoyne & Saunders, 2000; Green & Sobo, 2000). It is at this stage of the disease that the individual needs to begin the long battle of fighting the illness (McCain & Gramling, as cited in Green & Sobo, 2000). This stage of the disease is exhausting as the individual is faced with ever-increasing decline in physical health. It is also at this stage where the fact that one is HIV positive and living with HIV/AIDS could become “visible” through various external physical symptoms such as Kaposi’s sarcoma or increased need to take time off work to visit the doctor or hospital. During this stage the individual is faced with the stress of needing to monitor his or her symptoms constantly but

perhaps more distressing is the increased isolation and loneliness as the stigma of HIV/AIDS results in increased levels of rejection and abandonment (Alonzo & Reynolds, 1995).

In their research that resulted in the development of the HIV/AIDS Stress Scale, Pakenham and Rinaldis (2002) found that the three key dimensions of HIV/AIDS related stress are social stress, instrumental stress and emotional or existential stress. The social dimension of HIV/AIDS related stress was found to be the most distressing and includes issues relating to disclosure, isolation, stigma, discrimination and interpersonal relationships. The instrumental stress dimension includes issues around the day-to-day practicalities of living with HIV/AIDS such as finances, treatment and various problems that could arise as a result of interactions with the healthcare system. The emotional or existential dimension of HIV-related stress includes concerns about death, religion, grief or bereavement and the emotional adjustment required to live with HIV/AIDS. Thus it can be seen that PLWHAs are faced with multiple stressors from various sources. According to Namir, Wolcott, Fawzy and Alumbaugh (1987), "AIDS creates a multifaceted group of stressors that often exceeds the coping abilities people have developed before becoming ill" (p. 309). An understanding of these stressors and the impact these have on the physical and psychological well being should inform the psychosocial interventions of healthcare professionals in order to enhance the coping abilities of PLWHAs and ultimately enhance the quality of life of PLWHAs.

COPING WITH HIV/AIDS

As people start living longer with HIV/AIDS, it is going to become increasingly important that healthcare workers begin to consider ways in which we can enhance the coping mechanisms of PLWHAs as they face the continued stress of living with this chronic disease. Coping with and adapting to living with a chronic illness is a complex process. Feldman (1974) as cited in Tsasis (2000) defines adaptation to a chronic illness as

coming to terms existentially with the reality of chronicity as a state of being, discarding both false hope and destructive hopelessness, restructuring the environment in which one must now function... and most importantly, adaptation demands the reorganization of the self so that, there is a meaning and purpose to living that transcends the limitations imposed by the illness. (p. 555)

As can be seen in Folkman and Lazarus' definition of coping (Folkman & Lazarus, 1985), coping should be considered as a process where the individual attempts to adapt to stressors in his or her environment. The process of coping with HIV/AIDS is further complicated by the fact that the individual living with HIV/AIDS faces various differing stressors as the disease progresses. Research has shown that the way individuals cope while living with HIV/AIDS has an effect on their emotional and physical well-being and ultimately on their quality of life (Coetzee & Spangenberg, 2003; Friedland et al., 1996; Leslie, Stein, & Rotheram-Borus, 2002).

Coping with HIV/AIDS is a process that develops as the disease progresses. According to Green and Sobo (2000), "while it may be helpful to conceptualise adjustment to seropositivity as a series of stages, progression is not always linear and a palette of coping mechanisms may be selected from as challenges surface and recede" (p. 64). Initially the individual might cope with an HIV positive diagnosis by avoidance or denial which could be considered an unhelpful way of coping. However, at that point in the disease, this could be the only way of the individual to cope with the overwhelming nature of such a diagnosis (Coetzee & Spangenberg, 2003; Schreurs & de Ridder, 1997). Avoidance or denial as a coping mechanism can be considered as an "adaptive response that allows the individual to cope with the initial shock while buying time to make the necessary cognitive adjustment" (Coetzee & Spangenberg, 2003, p. 214). As the disease progresses the individual will begin to make use of more active, problem-focused coping strategies such

as seeking social support and finding ways to proactively manage the disease. The type of coping strategy employed by the individual depends on the nature of the stressful situation and the meaning that the individual attributes to the situation. If the situation is perceived to be uncontrollable then the individual is more likely to make use of emotion-focused coping strategies. Whereas, if the individual believes that he or she has some control over the stressful situation, then the individual is more likely to make use of problem-focused coping strategies (Folkman & Lazarus, 1985; Pakenham et al., 1994).

This is understandable in the context of HIV/AIDS since at the time of diagnosis the individual possibly feels that he or she has no control over the situation and thus makes use of emotion-focused coping strategies in order to regulate the emotional stress associated with an HIV positive diagnosis (Folkman & Lazarus, 1985). However, as the disease progresses and as the individual gathers more information about the disease, he or she is able to make use of active, problem-focused coping strategies. Folkman, Chesney, Pollack and Coates (1993) conducted research that examined the relationship between stress, appraised control and coping in a population of HIV positive and HIV negative homosexual men and found that when individuals perceived the stress as controllable, they were able to make use of problem-focused coping strategies such as "planful problem-solving, seeking advice and information, and reappraising the situation in a positive light" (p. 414). In the context of HIV/AIDS it would appear that emotion-focused and problem-focused coping strategies should not be considered as being mutually exclusive but these different coping strategies often co-occur and the one may influence and, in turn, facilitate the other (Carver & Scheier, 1994).

In research conducted by Pakenham, Dadds and Terry (1994) that investigated the relationships between the stage of the disease, social support, coping strategies and adjustment to HIV/AIDS, it was found that both emotion- and problem-focused strategies play a role in facilitating adjustment to the stress associated with HIV/AIDS. Hays, Turner and Coates (1992) reported similar findings in their research and concur that different coping strategies are used by PLWHAs at different points in the progression of the disease. Active, problem-focused coping strategies seem to be associated with better health outcomes than passive, emotion-focused coping strategies.

Research conducted by Namir et al. (1987) explored the relationship between various coping strategies and psychological and physical health and found that active, behavioural

coping strategies were associated with lower mood disturbance and higher self-esteem whereas avoidance coping was associated with a lower sense of self-esteem and more depressive symptoms. Kurdek and Siesky (1990) report similar findings in their research into the differences in the psychological adjustment of homosexual men who are HIV positive. They found that psychological well-being was associated with the "infrequent use of avoidance coping strategies" (Kurdek & Siesky, 1990, p. 846). Namir et al. (1987) suggest that "interventions that encourage problem solving, participation in decision making, and active coping strategies rather than passive acceptance of the illness, especially in the early stages of the illness, may be more helpful" (p. 326).

Heckman, Kochman, Sikkema, Kalichman, Masten, Bergholte and Catz (2001) investigated the effects of a coping improvement intervention on a sample of 16 HIV-infected adults. The aims of the ten session intervention were to enable the participants to accurately appraise sources of stress, to develop adaptive coping responses and to access social support resources in order to facilitate coping efforts. The participants completed an assessment before the intervention and the same assessment was completed after the intervention. The results suggest that after the intervention participants were able to cope with HIV-related stressors in a more adaptive manner in that they were able to engage in more active, problem-focused strategies. In addition the participant's perception of their social support network was more positive after the intervention and they displayed a renewed sense of optimism. These results confirm the findings of previous research that suggests that active positive coping strategies are positively related to a reduction in HIV-related stressors and ultimately psychological well-being (Hays et al., 1992; Hedge, 1990; Kurdek & Siesky, 1990)

The meaning that the individual attributes to HIV/AIDS and the stage of the illness will play a role in the coping strategy he or she adopts. As healthcare workers we need to be sensitive to the diversity of our client population and should not attempt to adopt a one-size-fits-all approach to helping people cope with HIV/AIDS. However, it is evident that an individual who adopts avoidance or denial as a coping strategy for an extended period of time may be placing him or herself at risk for adverse psychological outcomes that could ultimately affect his or her physical health. In working with PLWHAs it is important that one builds up a good relationship based on mutual trust. Once the foundations of such a relationship are laid one will be in a position to challenge attitudes and ultimately change behaviour that could be detrimental to the individual's health.

THE ROLE OF SOCIAL SUPPORT IN COPING WITH HIV/AIDS

The issue of social support is an important one in the field of HIV/AIDS. As the disease is so highly stigmatised, it places PLWHAs at risk of social isolation and subsequently in a position where they could be unable to access support (Namir et al., 1989). In South Africa where, despite attempts to destigmatise the disease, the issue of social support seems particularly pertinent. As the Department of Health has recently rolled out its national anti-retroviral programme, PLWHAs may begin to anticipate an increase in life expectancy. As more people start accessing anti-retrovirals, they will need more social support in order to enhance adherence to the medication as well as to assist them with coping with living longer with HIV/AIDS. As part of the anti-retroviral programme, the individual is required to attend various one-on-one counselling sessions as well as group sessions where the details of the programme are discussed. It would appear that the Department of Health has recognised the value of social support and the role that it plays in the treatment of HIV/AIDS. It therefore seems appropriate that as healthcare workers should endeavour to gain a deeper understanding of the role that social support can play in the lives of PLWHAs.

The buffering effect of social support

Social support can have a direct effect on health outcomes by alleviating distress and thus improving immune functioning. It can also provide a buffering effect by protecting PLWHAs from the stress and strain associated with HIV/AIDS (Cohen & Wills, 1985; Syrotuik & D'Arcy, 1984). Psychosocial resources such as social support mediate the affects of stressors and thus affect health outcomes positively (Peterson, Folkman, & Bakeman, 1996). The fact that there is a link between social support and positive health outcomes seems indisputable, however, it remains unclear exactly how social support influences health (Green, 1993). An explanation of the link between social support and health can be found in the field of psychoneuroimmunology and various studies have shown a link between having a supportive social network and immune function (Bastardo & Kimberlin, 2000; Leserman et al., 2000; Leserman, Perkins, & Evans, 1992;).

Social support as a coping mechanism

Seeking social support can be considered to be a coping mechanism and social support can also interact with an individual's coping response in order to assist the individual with coping with a stressful situation (Bloom, 1990; Thoits, 1986). Research conducted by

Pakenham et al. (1994) with a sample of 96 HIV positive homosexual men and a control group of 33 HIV negative men supports the idea that seeking social support as a coping mechanism has positive outcomes on psychological and physical health and that social support plays a role in facilitating social adjustment to living with HIV/AIDS. Hays, Turner and Coates (1992) conducted research that examined the impact of social support and HIV-related conditions on depression among 508 homosexual men in San Francisco. Their findings indicate the beneficial effects of social support in that the men who were satisfied with the social support they were receiving showed fewer depressive symptoms than those men who were dissatisfied with their social support. This study also highlighted the use of the different types of social support (emotional, informational and tangible or practical) at various points in the progression of the disease. The findings suggest that at the initial stage of diagnosis and during the early stages of the disease the individual may require more informational support. It would appear that gathering information about the disease and talking about the disease to other people helps people cope because it demystifies HIV/AIDS, it increases one's knowledge base about the disease and ultimately plays a role in decreasing anxiety and depression associated with HIV/AIDS (Hays et al., 1992; Kalichman et al., 1996; Tsasis, 2000). As the disease progresses and symptoms become severe, the individual is in need of emotional support such as nurturance, empathy, acceptance, affection and encouragement (Kalichman et al., 1996; Tsasis, 2000). This highlights an important point – the type of social support provided needs to match the demands placed by the stressor in order to effectively buffer the stress (Cohen & McKay, as cited in Hays et al., 1992). In the provision of social support we need to adopt an holistic approach in order to ensure that we meet the needs of the whole person and not only parts. All three types of social support are relevant to PLWHAs and it is important that we do not neglect any one at the expense of the other. As an example it is easy to provide tangible support in the form of giving food parcels, clothes, money or other practical things to PLWHAs but the provision of emotional support requires more effort and as such this area of social support could be neglected.

Social support enhances psychological well-being

Various studies have shown the role played by social support in reducing emotional distress and enhancing psychological well-being (Fleishman et al., 2000; Hays, Chauncey, & Tobey, 1990; Hays et al., 1992; Kalichman et al., 1996; Nott, Vedhara, & Power, 1995; Pakenham et al., 1994; Schrimshaw, 2002; Serovich et al., 2001). A South African study conducted by Cassidy (1991) as cited in (Schlebusch & Cassidy, 1995) examining the

interrelationships between psychological stress, social support, and emotional adjustment in a sample of HIV-positive individuals, yielded results indicating a statistically significant correlation between social support and emotional adjustment. Furthermore, the results showed that social support plays a “mediatory, stress-buffering effect between psychosocial stress and emotional adjustment” (Schlebusch & Cassidy, 1995, p. 28). By alleviating stress and reducing emotional distress such as seen in the symptoms of depression, social support can play a role in slowing down the progression of the disease to AIDS (Leserman et al., 1992; Leserman et al., 1999; Leserman et al., 2000). Leserman et al. (1992) sum up the effect of social support as it relates to the progression of the disease – “social support buffers some of the difficulties associated with the threat of AIDS and helps subjects maintain a positive and empowering approach to this disease” (p. 1519).

Social support improves quality of life

Friedland et al. (1996) conducted research that examined the relationship between coping, social support and quality of life in a sample of 120 HIV-positive people. Their findings suggest that coping and social support have the potential to mediate against the stressors of HIV/AIDS and ultimately to influence the quality of life of PLWHA's. Gielen, McDonnell, O' Campo and Faden (2001) confirmed the findings of Friedland et al, (1996) in their research that examined the relationship between psychosocial factors and health-related quality of life in a sample of 287 HIV-positive women. Women, who reported that they were satisfied with their social support network, had better mental health and quality of life. Bastardo and Kimberlin (2000) reported similar findings in their research that examined the relationships among health-related quality of life, social support, sociodemographic factors and disease-related factors in a sample of 118 HIV-positive individuals in Venezuela. The results yielded a significant positive association between social support and health-related quality of life with the greatest impact of social support being on the mental health domain.

The lived experience of social support

In a recent South African study Smyth (2004) explored the lived experience of social support for nine Black South African women living with HIV/AIDS with the aim of broadening understanding of the phenomenon of social support. The results of this phenomenological inquiry identified fourteen themes that constituted the lived experience of social support. The fourteen themes identified were: healthcare professionals, partners, family, motherhood, others, the role of support groups, story telling, education,

organisations, keeping busy and thinking positively, community neighbours, spirituality, being involved in the study and the extension of social support to others. Smyth (2004) suggests that these themes constitute the various aspects of social support. The results of this study indicate that social support is a “multifaceted, bi-directional concept made up of a network of relationships considered constituent aspects of social support” (Smyth, 2004, p. 132). Of note is the fact that participants experienced a polarity between supportive and unsupportive social support. Suggesting that when one considers social support both the satisfactory and unsatisfactory aspects need to be considered. The supportive or satisfying interpersonal relationships were those in which the participants social support needs of instrumental support, tangible assistance, informational provision and emotional connectedness were met. In planning interventions that aim to enhance social support healthcare workers should take cognisance of what constitutes helpful social support and find ways to meet these needs. Smyth’s research provides the South African healthcare worker with a valuable understanding of social support within the South African context and a model that can be used in planning interventions around the issue of social support with healthcare professionals and in support groups for PLWHAs.

The role of the healthcare professional

The results of the aforementioned studies represent an opportunity for healthcare professionals in the mental health field to intervene by assessing the PLWHA’s psychosocial resources such as social support network and pointing the individual in the direction to find the necessary social support in order to enhance the quality of life. The results of a study conducted by Bastardo and Kimberlin (2000) indicate that psychosocial support and specifically social support should be an important element in HIV/AIDS care in developing countries. Furthermore, the findings of Smyth’s (2004) research highlight the valuable role that healthcare professionals (doctors and nurses) and lay counsellors can play in meeting the social support needs of PLWHAs in the South African context. Thus it can be seen that social support can and should play an important part in the management of HIV/AIDS in the South African context. This may become increasingly important as the issue of quality of life of PLWHAs becomes more of an issue as life expectancy increases due to the effects of the introduction of anti-retroviral medication.

Who provides social support to PLWHAs?

The provision of social support to PLWHAs may enhance their quality of life and over time, retard the progression of the disease. But the question arises as to who is in the best position to provide such support to PLWHAs and who would PLWHAs turn to for social support?

Research suggests that PLWHAs receive most of their social support from friends, partners or other organisations rather than from their immediate family and that they perceive friends to be more supportive than family members (Barbee, Derlega, Sherburne, & Grimshaw, 1998; Burgoyne & Saunders, 2000; Crystal & Kersting, 1998; Friedland et al., 1996; Hays et al., 1990; Schwarzer, Dunkel-Schetter & Kemeny, 1994; Serovich et al., 2001). This represents an opportunity for healthcare workers to initiate structures at the primary level within the healthcare system that will meet the social support needs of PLWHAs.

The role of support groups

Many clinics in the Western Cape have formed support groups for PLWHAs and these groups have become a source of support for many PLWHAs who fear the attitudes of their family and other members of the community towards HIV/AIDS. Kalichman et al. (1996) conducted a pilot study examining the effect of support groups on the lives of PLWHAs. Their findings suggest that people who attended support groups showed less emotional distress and were less likely to adopt avoidant coping strategies. Their qualitative analysis indicated that for most people the benefits of belonging to a support group included "sharing feelings, relief from feeling alone, obtaining information on new treatments and different approaches to care, and obtaining answers to questions" (Kalichman et al., 1996, p. 596). According to Smyth (2004), support groups play a critical role in the lived experience of social support as the sense of universalism and belonging derived from such groups made the PLWHA feel that she was not alone in her experience of HIV. Support groups provide a space for people to connect with others who share similar experiences, they provide "powerful communicative opportunities for individuals to regain a sense of self, community, and control" (Frey, Query, Flint, & Adelman, 1998, p. 133). They also play a role in reducing the sense of alienation and loneliness many PLWHAs experience and have been shown to offer caring, supporting and empowering experiences for PLWHA (Blom & Bremridge, 2003).

In South Africa with its ever increasing HIV/AIDS population support groups and the creation of “helping communities” present an opportunity for psychologists to put their competencies to use (D’ Augelli, 1990). According to D’ Augelli, psychologists possess many unique competencies such as needs assessment and analysis, programme development and implementation as well as programme evaluation which could be employed in addressing the multiple problems created by the HIV/AIDS epidemic. In traditional African culture the concept of community is considered very important and it therefore makes sense that psychologists attempt to consider ways in which the broader community may become involved in the treatment and management of HIV/AIDS.

Unsatisfactory social interactions

Whilst it seems clear that social support and the maintenance of a social network can be beneficial, there are some social interactions which might not be that helpful to the PLWHA. Ingram, Jones, Fass, Neidig and Song (1999) in their research that examined the effects of negative social interaction on PLWHAs identified insensitivity, forced optimism, disconnecting and blaming as unsupportive or upsetting responses to the PLWHA. Furthermore, their findings suggest that unsupportive, negative social interactions were associated with an increase in depressive symptoms and other negative affective states (Ingram et al., 1999). Further research by Song and Ingram (2002) examined the relationship between perceptions of the availability of social support and enacted unsupportive social interactions and how these related to anxious and depressive mood among a sample of 116 African Americans. They found that unsupportive social interaction was associated with greater levels of mood disturbance and in addition unsupportive social interaction was also positively related to the use of the coping strategies of denial and disengagement which in turn were associated with greater mood disturbance (Song & Ingram, 2002).

Research conducted by Hays, Magee and Chauncey (1994) explored how 25 HIV positive homosexual men experienced their social support networks. The participants were asked to describe specific interpersonal exchanges that they found to be helpful and unhelpful. The results indicated that there were twelve main categories of helpful behaviours namely providing encouragement, companionship, information, practical assistance, material aid, philosophical perspective, support for other network members, expressing concern, sharing feelings, acting as role model, allowing reciprocity and interacting naturally. The unhelpful behaviours reported by the participants included pessimism, physical avoidance,

criticising one's response to AIDS or medical treatment, making unreasonable demands, patronising attitude, rude comments, insincerity, breaking confidentiality, acting judgmental or ashamed. Smyth (2004) reports similar findings in her research on the lived experience of social support where her findings show that participants experienced a polarity between supportive and unsupportive social support. The results yielded from such research provides the healthcare worker with an insider's view of what it means to be living with HIV/AIDS and how PLWHAs experience social support. Such knowledge should inform our psychosocial interventions in order to ensure that we adequately meet the social support needs of PLWHAs.

Close relationships from which people derive much of their social support can be difficult at times especially when these are fraught with conflict. When close relationships are strained they become a source of stress and could thus diminish the positive benefits of social support (Fleishman et al., 2000; Harvey & Wenzel, 2002; Smyth, 2004). PLWHAs need to be empowered with skills to help them deal with conflict and other difficulties in relationships and thereby reduce the stress associated with stressful personal relationships. Such "relationship maintenance skills" (Harvey & Wenzel, 2002, p. 137) can be useful in preserving relationships over the long term and ultimately maintain the positive social support that the PLHWA derives from such close relationships. Social support, when not provided in a sensitive and sincere manner, can have negative outcomes and may in the long run prove to be destructive and ultimately detrimental to the PLWHA's health and quality of life. Therefore in considering the role that social support can play in enhancing the physical and psychological health of PLWHAs, it is important that healthcare workers take cognisance of both the positive and the negative effects of social support and find ways to mitigate the possible negative effects of social support.

Social support has many positive, beneficial outcomes in respect of physical and psychological health and can ultimately improve the quality of life for PLWHAs. According to Tsasis (2000), "when levels of support are sufficiently strong, they may provide the central meaning of a person's life and thus diminish the perceived impact of almost any adversity, minimizing the individual's level of stress" (p. 556).

The review of the literature on social support and HIV/AIDS indicates that most of the research has been conducted on samples that are American, white and homosexual and as such the findings of the research needs to be generalised with caution. There appears

to be limited research on social support and HIV/AIDS in the South African context and this represents an opportunity for social scientists to start conducting research into this area which could play a key role in the management of the disease in the long run.

PRACTICAL IMPLICATIONS AND RECOMMENDATIONS

HIV/AIDS presents psychologists with many opportunities to put their competencies to use in creative ways. Previously psychologists mostly played a role in pre- and post-test counselling and ongoing supportive counselling for people living with HIV/AIDS. However, there has been a shift and psychologists are now becoming involved in the development of training programmes for lay counsellors, the running of support groups and in the provision of mentoring and supervision for lay workers in the field. If psychologists are to enhance the quality of life of PLWHAs, more will be required of the profession. In the past psychology has been accused of “marginalizing itself from the majority in South Africa” (Lindegger & Wood, 1995, p. 8). Psychologists run the risk of continuing along the same path unless attempts are made to start addressing the psychosocial needs of people living with HIV/AIDS.

The mental health consequences arising from the HIV/AIDS pandemic present mental health professionals with an enormous challenge (Freeman, 2004). The solutions required to minimise the effects of these mental health consequences perhaps lie beyond the scope of direct mental health interventions. However, mental health professionals need to rise to the challenge and take responsibility in order to prevent a potential “mental health catastrophe” (Freeman, 2004, p. 156). Morgan (2001) sums up the situation when he states that “(t)o not address the effects of the pandemic is like doing nothing during apartheid or the holocaust” (p. 20).

Leverage points for psychosocial interventions

Coping, social support and challenging cognitions and beliefs have been identified as leverage points for psychosocial interventions (Schmitz & Crystal, 2000). Healthcare professionals need to acknowledge the diversity of responses that people have to living with HIV/AIDS and respect the fact that it is highly unlikely that a one-size-fits-all model to assist PLWHAs to cope with the stress of living with HIV/AIDS can be created. However, healthcare professionals can encourage people to change their attitude towards living with HIV/AIDS and not view an HIV-positive diagnosis as a death sentence but rather to reframe this crisis as an opportunity for personal growth and challenge and in so doing encourage a “fighting spirit” (Coetzee & Spangenberg, 2002; Leserman et al., 1992).

Cognitive-behavioural interventions

Cognitive-behavioural interventions may be employed in order to assist PLWHAs identify stressors in the daily lives and teach them skills such as progressive relaxation, cognitive reframing and problem solving to aid them in coping with such stressors (Folkman et al., 1993; Hedge, 1990; Sikkema et al., 2000). The use of active, problem-focused coping such as seeking various forms of social support, proactively managing the disease and engaging in spiritual activities should be encouraged (Coetzee & Spangenberg, 2002).

Assessment and provision of social support

In terms of the provision of social support, healthcare workers need to assess the amount and type of social support available to the PLWHA and in addition need to determine whether the social support available is helpful or unhelpful (Burgoyne & Saunders, 2000; Pakenham et al., 1994). It may be helpful to conduct a needs analysis in order to identify the type of social support required by the PLWHA and where there are gaps as well as deficiencies in the person's social support network in order that these needs can be appropriately addressed. In the South African context poverty is a major challenge facing PLWHAs and the provision of tangible social support such as food parcels is greatly needed. Various faith-based organisations have initiated the concept of "love packs" which contain various items of food, bedding and other provisions to care for PLWHAs or to enhance their nutrition. Healthcare workers should become informed about organisations that offer such tangible social support to PLWHAs in order to ensure that they receive the appropriate tangible support. If tangible social support needs are not adequately met this could result in basic self-care needs such as nutrition and personal hygiene being neglected. This in turn could have adverse effects on the health of PLWHAs (Burgoyne & Saunders, 2000). Informational and emotional support needs can be met in support groups for PLWHAs, by engaging in other social activities such as playing sport or by involvement in a spiritual community. Simoni, Martone and Kerwin (2002) highlight the important role that spirituality can play in coping with the stress of HIV/AIDS and recommend that healthcare workers engage with religious professionals in order to find ways of addressing the spiritual needs of PLWHAs. In assessing and providing social support, the healthcare worker should endeavour to be aware of and respect the specific needs of the PLWHA and not assume that all PLWHAs have the same social support requirements.

Psychoeducational interventions

Psychoeducational interventions such as lifeskills programmes can serve as a way to enhance the coping skills of PLWHAs by equipping them with skills such as stress management, conflict resolution, assertiveness training and communication skills to mention a few. Psychologists have the competencies to develop and implement such programmes and should attempt to start finding opportunities to put these competencies to use.

In addition to educating PLWHAs, psychologists can also play a role in raising the awareness levels of other healthcare professionals such as doctors and nurses in terms of the vital role they can play in the provision of social support to PLWHAs. Smyth (2004) proposes a brief four-session intervention for healthcare professionals aimed at developing an awareness of the important role they play in the lives of Black South African women. The aim of this intervention is to sensitise the healthcare professional to the needs and context of the HIV positive woman and to start dialoguing around how healthcare professionals can address the various needs of the PLWHA other than the medical needs. This intervention could be adapted and applied for other groups within the South African context. In a country where few people have access to mental health professionals, psychologists can play a role in sharing psychology with other healthcare professionals and in so doing enhance the quality of care provided by these healthcare professionals.

Training and support

Psychologists who work within training organisations such as the AIDS Training Information and Counselling Centres (ATICC) need to understand the issues of social support and need to include such issues in the training of lay counsellors who do pre- and post-test counselling. Smyth (2004) found that lay counsellors play a pivotal role in the lived experience of social support. It is therefore important that lay counsellors and other healthcare workers who conduct pre- and post-test counselling be trained adequately in order to deliver a service that is effective and that meets the needs of the person who is diagnosed HIV positive. One of the aims of pre-test counselling is to provide the individual who is coming for an HIV test with information about HIV/AIDS (van Dyk, 2001). Therefore it is crucial that this process not be rushed but that the counsellor takes time to provide accurate information and correct any misinformation that the person has about HIV/AIDS (Smyth, 2004). During the post-test counselling Smyth suggests that the counsellor mention the various forms of social support that other PLWHAs have found useful in an

attempt for the person who has been diagnosed HIV positive to start identifying potential sources of social support within his or her environment. Follow-up counselling sessions should be scheduled with the newly diagnosed HIV positive individual. Smyth recommends that during these follow-up sessions the counsellor assess whether or not the social support needs of the individual are being met and if these needs are not being met adequately the counsellor should be able to refer the individual to organisations who will best be able to meet these needs. It is recommended that these issues be emphasised in lay counsellor training programmes and that training organisations schedule follow-up, refresher courses for lay counsellors they have trained in order to update them on any new issues and to ensure that their skills are kept up to date. Research conducted by van Dyk and van Dyk (2003) suggests that one of the reasons that people do not willingly go for HIV tests is because they do not trust the healthcare professionals and they fear discrimination and rejection by the latter. The lay counsellor can act as a buffer between the healthcare professional and the client and therefore it is vital that these counsellors are adequately equipped to offer an effective counselling service and create an environment where the individual feels safe and experiences empathy and warmth.

Various researchers have indicated that support groups have beneficial outcomes for the PLWHA (Blom & Bremridge, 2003; D'Augelli, 1990; Frey et al., 1998; Kalichman et al., 1996; Smyth, 2004). It is recommended that training on the facilitation of support groups be included in lay counsellor training programmes and that support group facilitators be mentored and supervised on a regular basis (Smyth, 2004). Psychologists or social workers could do such mentoring and supervision. Smyth (2004) proposes that support groups have discussions around the issues of their experience of social support in order to enable group members to develop a deeper understanding of the world of interpersonal relationships that constitute social support. In this regard she has developed a ten-week programme focusing on the fourteen themes that emerged during her research (see Smyth, 2004, for detailed information).

Space for story telling

Space needs to be created for PLWHAs to tell their stories and to share their experiences of living with HIV/AIDS. Such space can be created in individual counselling sessions, in the context of a support group or by involvement in projects such as the Memory Box Project (Morgan, 2001; Smyth, 2004). By creating openness towards talking about

HIV/AIDS psychologists and healthcare workers can play a role in demystifying and perhaps destigmatising the disease.

The role of other organisations

Psychologists who work with PLWHAs should be informed of other organisations or agencies that offer support to PLWHAs and make the necessary referrals to such organisations. Smyth (2004) identified the important role that other community and faith-based organisations such as the Treatment Action Campaign (TAC), the Vaccine Project, Love Life and Social Services played in the lived experience of social support for Black South African women. These organisations were seen to meet various social support needs for the PLWHA depending on the nature of the organisation. It is impossible for psychologists to be everything to everybody and therefore a multidisciplinary approach needs to be adopted in managing HIV/AIDS and links with non-governmental and faith-based organisations in the community need to be built in order to tap into the resources that exist within these organisations. A directory of organisations that provide support to PLWHAs would be a useful tool for all psychologists as this will empower them with information to make appropriate referrals or to enhance their knowledge about HIV/AIDS.

HIV Helping Networks

D' Augelli (1990) suggests that community psychologists start getting involved with various organisations such as formal community groups, support and self-help groups and other informal support networks in order to create a "helping community" that integrates medical and other social services. In his article he outlines how such a "HIV Helping Network" (p. 341) can operate and what types of interventions the network will offer. The idea behind these helping communities is that professionals from various disciplines start engaging with one another and with the various community-based organisations in order to meet the multiple medical, psychosocial and spiritual support needs created by the HIV/AIDS epidemic. D' Augelli proposes that the different interventions implemented by the network meet the objectives of problem solving, enhancing skills or competence in order to improve individual functioning, education, prevention, advocacy and resource provision. This model provides a holistic approach to dealing with the problems brought about by HIV/AIDS. In the South African context where, particularly in African culture, a strong emphasis is placed on community and collaboration, the idea of such HIV helping communities or networks seems plausible. However, the dynamics that exist between the various professional groups that would need to be involved in such networks could present

some difficulties. This perhaps presents one of the greatest challenges facing professionals working in the field of HIV/AIDS – to put aside petty differences and divisions, to focus on the bigger picture and ultimately the greater good. Failure to start working together will mean the wasting of precious time and resources which are crucial to the fight against HIV/AIDS.

Future research

A further opportunity for psychologists and other social scientists is in the area of research. The literature review on stress, coping and social support suggests that limited research has been conducted into these fields in the South African context. One of the ways that psychologists can put their competencies to use is to bolster the body of knowledge on HIV/AIDS and in so doing create a deeper understanding of the psychosocial aspects associated with HIV/AIDS. Such knowledge will be useful in raising awareness of these issues and also planning appropriate psychosocial interventions that are relevant to the South African context.

Much of the social support research has been conducted on samples consisting of homosexual men and it seems that there is a need for research to be conducted on other samples so as to gain a broader understanding of how the issue of social support affects other population groups.

Research that has been or will be conducted on mental health and HIV/AIDS needs to be translated into published academic literature and/or policy debates and practices (Freeman, 2004). Such research needs to start influencing the national HIV/AIDS agenda and become part of a national HIV/AIDS policy in which mental health issues are integrated with other issues related to HIV/AIDS. Freeman (2004) notes that “(t)he urgency of the situation necessitates much more research, much more dialogue and a greater integration of mental health issues into a national AIDS policy” (p. 156).

CONCLUSION

The HIV/AIDS pandemic presents a crisis to healthcare workers in South Africa and as was suggested earlier in this paper, perhaps the challenge for healthcare workers is to reframe this crisis and to see it as an opportunity for growth and challenge. If, as healthcare workers, the monster that is HIV/AIDS continues to overwhelm us, we will be lulled into a state of inertia and hopelessness. The challenge is to maintain a sense of hope and optimism, to tap into the collective fighting spirit that exists among healthcare workers and together continue the battle against HIV/AIDS.

This paper has presented a framework for understanding the stress of living with HIV/AIDS and the role that social support can play in mediating in the stress response and as a coping mechanism. Coping and social support have been identified as leverage points in psychosocial interventions for people living with HIV/AIDS and this presents psychologists with many unique opportunities for planning appropriate and effective interventions. Various practical implications and recommendations have been suggested as guidelines for planning and implementing psychosocial interventions for PLWHAs.

There are many creative ways of using the competencies and skills of psychologists to promote better quality of life for people living with HIV/AIDS. As individuals working in the field of psychology we need to be aware of the difference that we can make to PLWHAs and we need to proactively rise to the challenge that faces us in order to positively influence the lives of people living with HIV/AIDS.

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