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Coping styles and quality of life in people with HIV/AIDS: a review

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In the midst of the dramatic global escalation of the HIV/AIDS pandemic, the relative longevity of patients continues to increase. The success with which one manages to cope with the continuous stress attached to HIV/AIDS impacts directly on one's quality of life. It is therefore of major importance to determine which coping styles correlate positively with quality of life in people with HIV/AIDS. In general, the research literature indicates that problem-focused, active coping styles are superior to emotion-focused, passive coping styles, including avoidance. However, interesting contradictory findings have come to light in South Africa, namely that an avoidant coping style also seems to be beneficial in the African socio-cultural context.

Streshanteringstyle in die lewenskwaliteit van mense met MIV/VIGS: 'n oorsig

Te midde van die dramatiese wêreldwye eskalasie van die MIV/VIGS-pandemie, is daar 'n volgehoue toename in die oorlewingstyd van mense wat aan die siekte ly. Die sukses waarmee 'n individu die voortdurende stres verbonde aan MIV/VIGS hanteer, het 'n direkte impak op sy of haar lewenskwaliteitervaring. Dit is dus essensieel om vas te stel watter streshanteringstyle positief verband hou met beter lewenskwaliteit vir mense met MIV/VIGS. Die bevindinge in navorsingsliteratuur dui oor die algemeen daarop dat probleemgeoriënteerde, aktiewe streshanteringstyle meer doeltreffend is as emosiegeoriënteerde, passiewe streshanteringstyle, insluitend vermyding. In Suid-Afrika het egter interessante teenstrydige bevindings aan die lig gekom, naamlik dat vermyding skynbaar ook in hierdie verband voordelig is binne die sosiokulturele konteks van Afrika.

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The dramatic global escalation of the HIV/AIDS pandemic has been termed a slow-wave disaster, causing the devastation of individuals, families, communities and economies (Jackson & Kerkhoven 1995). Despite the relatively late introduction of the pandemic into South Africa, it has spread alarmingly, particularly among heterosexuals. According to recent global figures released by the World Health Organisation, 70% of the 33.4 million people living with HIV/AIDS are in sub-Saharan Africa (Allen *et al* 2000). Official projections commissioned by the United Nations Development Programme predicted that South Africa's HIV seropositivity figure for 2002 would be in the region of 4.2 million adults and children. It is disturbing to note that this figure had already been exceeded by the year 2000 (Whiteside & Sunter 2000).

The most recent figures released by the government suggest that 4.7 million South Africans (one in nine) are currently infected with the virus. It is estimated that by the year 2006 no less than 17% of the population will be infected (Swanepoel 2001). Shocking as these figures may be, they are considered conservative by independent statisticians. A figure in the region of 5.3 to 5.4 million currently infected is regarded as more realistic (Beresford 2001).

While research findings regarding the prevention and cure of HIV/AIDS remain inconclusive, the survival time of individuals with an HIV diagnosis continues to increase (Catalan *et al* 2000). Consequently the media, as well as the health care services, have made a conscious shift away from issues of death and dying towards a focus on lifestyle changes in the process of living with HIV/AIDS. What remains unaltered, however, is the personal struggle and severe stress linked to an HIV diagnosis. The stress results not only from the physiological challenges of the disease but also from the socio-economic and interpersonal consequences associated with an illness that is stigmatised, progressive and chronic ill. The rapid advance of the disease is characterised by a fluctuating course involving periods of good health followed by periods of ill-health. HIV-positive people face an uncertain future, not only with regard to their physical well-being, but also because of the constant flux of new discoveries, new therapies and complex arguments concerning the aetiology, progression and management of the disease (Chidwick & Borrill 1996).

HIV/AIDS thus represents a major life crisis with a unique set of stressors impacting on both the individual and the community. Due to its chronic nature, its course is characterised by a series of health-related and other stress peaks, thus making any equilibrium achieved tentative and fragile, at best (Moos & Tsu 1977).

1. The importance of quality of life to people with HIV/AIDS

The success with which a person manages to live with the ongoing stress attached to HIV/AIDS impacts directly on his/her quality of life. Quality of life is a relatively new concept in health care research and has its origin in the field of oncology. It became clear that the value of cancer treatment should be judged not by survival alone, but by the quality of that survival (Grimes & Cole 1996). It was soon realised that this concept had a broader application to other chronic illnesses such as HIV/AIDS. With growing understanding of HIV/AIDS, researchers and health care professionals recognised that survival time is not only a question of duration, but also of the quality of life (Catalan *et al* 2000).

Until recently, the quality of life has generally been conceptualised as a functional state rather than as a subjective construct reflecting attitudes and perceptions (Grimes & Cole 1996). Functional status refers to a person's ability to function effectively within a given role or activity. In the context of illness it refers broadly to what has been termed "self-help", describing the ability to manage adversity during illness. Such self-help functionality includes mobility, physical ability and social activity (Grimes & Cole 1996). Although functional status is logically related to the pathology, progression and symptomatology of the disease, there is sufficient evidence to argue that a person's perceived quality of life differs conceptually from his or her functional status. Even though daily functioning may be impaired, one may still take pleasure and find satisfaction in life. In illness, quality of life therefore refers less to functional status and more to the subjective appraisal of one's well-being and degree of satisfaction (Grimes & Cole 1996). Thus a subjective sense of purpose and meaning in life is dependent on the patient's appraisal of his or her overall physical,

psychological and social functioning and impacts directly on his or her morale, happiness and satisfaction with life (Friedland *et al* 1996). Retaining a sense of personal well-being and purpose in life while living with HIV/AIDS is enormously challenging, but crucial to ensuring an optimal quality of life during a limited period.

Although initial HIV research focused primarily on measuring the effectiveness of medical and pharmacological interventions (Hays & Shapiro 1992; Wu & Rubin 1992), there is growing recognition that the quality of life is an important outcome in and of itself (O'Keefe & Wood 1996). Facing years of declining health and an escalation in debilitating infections, the importance of maintaining an optimal quality of life for people with HIV/AIDS is self-evident.

2. Styles of coping with the stress of HIV/AIDS

The efficacy with which one copes with the stress of living with HIV/AIDS plays a crucial role in determining one's quality of life. In the research literature, depression and anxiety — generally considered to be the most prominent emotional manifestations of stress (Lazarus 1993; Lovibond & Lovibond 1995) — are described as the two most common psychological reactions to a diagnosis of HIV or AIDS (Faithfull 1997; Kaplan *et al* 1997). Coping with stress, in terms of Lazarus & Folkman's (1984) transactional model, refers to one's continuous cognitive and behavioural attempts to manage the demands of a situation that one perceives as taxing or stressful.

Coping styles play an important role in one's physical and psychological well-being in stressful circumstances (Endler & Parker 1990; Miller *et al* 1988). The nature of one's circumstances or of a specific stressor partly determines which specific coping style will be employed (Lazarus & Folkman 1984). The use of coping strategies therefore probably varies according to the demands of the situation as well as the course of the coping process. It is also important to bear in mind that no coping strategy is inherently positive or negative. The effectiveness of a particular strategy is determined by one's flexibility in selecting and implementing different strategies, as well as by the synergy between the specific coping strategy, one's appraisal

of the stressor and the characteristics of the stressor (Hobfoll 1998; Livneth *et al* 1996).

Following the initial appraisal of a stressful situation —— in this case an HIV diagnosis —— and the subsequent appraisal of one's resources for coping with it, a specific coping style is selected (Schreurs & De Ridder 1997). The identification of desirable coping styles as a means of ensuring an optimal quality of life has recently become particularly prominent in international HIV/AIDS research. There is an emphasis on the need for an in-depth understanding of how individuals cope with HIV/AIDS-related stressors, to facilitate the development of appropriate psychosocial interventions (Pivar & Temoshok 1990). Such an understanding could also serve as a means of identifying and supporting individuals whose coping styles lead to increased psychological, social or physical vulnerability.

Coping styles have been grouped into various categories in the research. Two of the most common categorisations are problem-focused versus emotion-focused styles (Coyne & Downey 1991; Endler & Parker 1990), and active versus passive styles (Goodkin *et al* 1992; Moneyham *et al* 1998). A specific coping style, namely avoidance, has been categorised as passive and emotion-focused. Although more extensive categorisations of coping models have been suggested in the research literature (cf Hobfoll 1998; Livneth *et al* 1996; O'Brien & Delongis 1996), this article will utilise the two basic, simplified distinctions, since research on coping styles in HIV/AIDS patients has, up to now, centred on these broad categories. In addition, the "fighting spirit" and denial will be discussed as they have been identified as coping styles and investigated in HIV/AIDS research. Questions will also be raised as to the relevance of international findings within the South African context, as well as their implications for intervention strategies.

2.1 Problem-focused versus emotion-focused coping styles

Macro-level analysis has led to a distinction between problem-focused and emotion-focused coping (Lazarus & Folkman 1984). This is the most influential conceptualisation made thus far (Coyne & Downey 1991), and one on which consensus has been reached in the coping literature (Endler & Parker 1990). The distinction is drawn on the basis

of function: problem-focused coping consists of cognitive problem-solving efforts and behavioural strategies aimed at managing the problem causing stress, while emotion-focused coping refers to cognitive and behavioural efforts which serve to manage or reduce the stress or negative emotions caused by the problem (Lazarus & Folkman 1984). Holahan & Moos (1987: 946) distinguish between problem-focused and emotion-focused coping as "strategies that are active in nature and oriented toward confronting the problem" and "strategies that entail an effort to reduce tension by avoiding dealing with the problem". Problem-focused coping styles have been shown to be more effective in circumstances that are perceived by the individual as amenable to change, while emotion-focused coping styles, such as acceptance and seeking social support, are associated with positive outcomes in circumstances perceived as immutable (Aldwin 1994; Carver *et al* 1989).

It seems that confronting and dealing with the stress of an HIV/AIDS diagnosis in a problem-focused manner generally not only facilitates acceptance, but also empowers patients to take on the challenges of their condition in a pro-active and realistic manner. Several researchers support this assumption and suggest that a good quality of life depends on the HIV-positive person's ability to adopt problem-focused coping strategies. The use of such coping strategies, such as effective stress management and perceived control, seems to have a significant positive influence and shows a positive correlation with an improved quality of life in HIV/AIDS patients. Conversely, failure to use these strategies has been found to have a significant negative effect (Chidwick & Borrill 1996).

In a recent longitudinal study of 138 HIV-infected patients in Nebraska, Swindells *et al* (1999) found that an improved quality of life was associated with problem-focused coping, while emotion-focused coping, such as avoidance, was associated with hopelessness, loss of motivation and negative feelings about the future, and thus predicted a poorer quality of life. In accordance with these findings, De Genova *et al* (1994) also found a positive correlation between emotion-focused coping and depression.

2.2 Active versus passive coping styles

As is the case with problem-focused coping, an active coping style implies a pro-active cognitive and behavioural engagement with the realities of being HIV-positive, and correlates strongly with an improved quality of life (Abetz *et al* 1998; Friedland *et al* 1996; Heckman *et al* 1997).

An active coping style has also been associated with an internal locus of control (Brieger *et al* 1996; Heckman *et al* 1997; Singh *et al* 1998). Locus of control refers to one's beliefs or cognitions with regard to the ways in which a given outcome occurs. An internal locus of control suggests that the outcomes occur due to something inside oneself and under one's control, while an external locus of control implies that the outcome is dependent on other people or factors beyond one's control. A sense of hopelessness or helplessness is likely to develop in a person with an external locus of control, who does not have a sense of mastery or a belief in his/her ability to control his/her world and affect personal outcomes (Lefcourt 1981). In accordance with this hypothesis, hopelessness, loss of motivation and negative feelings about the future were shown to be predictors of a poorer quality of life in people with HIV/AIDS (Grassi *et al* 1998; Osowiecki *et al* 2000; Singh *et al* 1998).

In a study of 167 men Pepler *et al* (1998) found that active coping and a sense of control were associated with health in HIV-positive individuals. They also concluded that when passive or avoidant coping strategies were employed, respondents often recognised the ineffectiveness and undesirability of these patterns, which potentially added to their frustration with the illness and exacerbated their emotional distress. This study therefore emphasised not only the importance, but also the perceived effectiveness of active coping.

Passive coping, on the other hand, has been linked not only to a poorer quality of life but also to the clinical progression of HIV to AIDS (Byrnes *et al* 1997; Goodkin *et al* 1992). Moneyham *et al* (1998) investigated the effectiveness of active and passive coping styles in a sample of 264 women. Active coping, which included activities such as seeking social support, managing the illness and engaging in spiritual activities, appeared to serve a protective function

in that emotional distress decreased with more utilisation of active coping, even as physical symptoms increased. Passive coping, such as avoidance behaviour, gave no such protection against emotional distress. Interestingly, the use of avoidance coping decreased and active coping increased as the physical condition worsened, suggesting that active coping is more likely to be used as symptoms increase.

In a four-year longitudinal German study, 43 subjects reported on their quality of life, depressive reactions and coping styles. A decrease in evasive-regressive (passive) coping in favour of palliative and goal-oriented (active) coping strongly predicted an improved quality of life (Brieger *et al* 1996). Similar findings were obtained in another longitudinal German study of 61 HIV-positive people. Evasive-regressive coping was found to be positively correlated with a reduced quality of life and was most commonly used by intravenous drug users (Leiberich *et al* 1993).

The passive coping style of escape-avoidance has been associated with symptoms of psychological distress (such as depression and self-blame), an external locus of control and a reduced quality of life in general (Chidwick & Borrill 1996; Grassi *et al* 1998; Kalichman *et al* 1996; Singh *et al* 1998; Swindells *et al* 1999). Siegel *et al* (1997) found that escape-avoidance coping was closely associated with negative emotion in a sample of HIV-positive women. In a study of subjective attribution theories on coping and psychological functioning among homosexual men with HIV, self-blame was associated with an avoidant coping style, and both of these were associated with a depressive mood and dissatisfaction with life (Clement & Schonneson 1998). A Japanese study of 50 HIV-positive patients confirmed that depressive symptoms and somatic complaints, signalling a poor quality of life, had a significant positive correlation with avoidance coping responses (Fukunishi *et al* 1997).

2.3 The "fighting spirit" coping style

Some researchers identified a specific mental attitude towards HIV/AIDS which they conceptualised as a "fighting spirit." This coping style can be described as a confrontative, goal-orientated style of coping with the disease. In this regard Grassi *et al* (1998) found an association between lower "fighting spirit" scores, greater hopelessness

and elevated psychological morbidity. "Fighting spirit" was found to be the more adaptive end of the continuum and helplessness/hopelessness the less adaptive.

Kelly *et al* (2000) conducted an Australian study of 164 HIV-positive men, measuring their psychological adjustment to the condition. The four factors identified were hopelessness, "fighting spirit", personal control and minimization. "Fighting spirit" emerged as a predictor of psychological resilience, whereas hopelessness was significantly associated with psychological symptoms and concurrent major depression.

In a study of the "fighting spirit" coping style among 58 HIV-positive women, it was found that low scores on loneliness, anger and depressive symptoms significantly predicted high scores on "fighting spirit" (Nannis *et al* 1997). Leserman *et al* (1992) reported that adopting a "fighting spirit", reframing stress to maximize personal growth, planning a course of action, and seeking social support were associated with a better prognosis. Thus "fighting spirit", as a specific form of problem-focused or active coping, has been found to correlate positively with an improved quality of life in HIV/AIDS (Grassi *et al* 1998; Zander *et al* 1993).

2.4 Denial as a coping style

Denial, as a form of escape-avoidance coping, has been the subject of much research and deserves more in-depth exploration. According to Hackl *et al* (1997), denial is an emotion-focused coping style characterised by the use of distractions, blocking or blunting techniques, and non-acceptance of the HIV/AIDS diagnosis and its consequences. The theoretical framework pertaining to the concept of denial had its origin in grief work, where it was argued that the presence of avoidance and denial prevented the individual from fully negotiating the bereavement crisis (Lazarus 1981).

It has been suggested that denial is the opposite of vigilance. Janis & Mann (cited in Horowitz 1978) point out that vigilance is desirable as it mobilises a search for information and the consequent weighing-up of alternative coping strategies. Denial obstructs successful mastery of a threat by preventing successful cognitive coping

prior to a stressful confrontation. Research studies in the fields of oncology and cardiology confirmed these findings, as denial of initial signs of illness resulted in delayed medical intervention and a poorer prognosis (Lazarus 1981).

A seven-year prospective study conducted in the USA confirmed that a more rapid progression of AIDS was associated with the use of denial as a coping mechanism (Gale 2000). In addition, a study conducted in a homosexual symptomatic seropositive male community revealed that denial was closely associated with impulsive, self-destructive behaviour such as drug/alcohol abuse or high-risk sexual behaviour (Pivar & Temoshok 1990), which in turn led to a reduction in the quality of life.

On the other hand, denial can also be viewed as an adaptive response that allows the individual to cope with an initial shock while buying time to make the necessary cognitive adjustment. Lazarus (1981) distinguishes between denial with a negative outcome and denial with a positive outcome. He suggests that denial may be helpful within a limited time-frame, but that it may become dysfunctional as time passes. Kubler-Ross (1970) refers to the temporary disavowal of reality as a means of getting through the devastating early period of loss and threat, before reaching the later stage of acknowledgement and adjustment.

3. South African research on coping styles in people with HIV/AIDS

The survey of the literature presented above highlights the desirability of a problem-focused or active coping style as opposed to an emotion-focused, passive or avoidant style of coping with the stress associated with HIV/AIDS. This insight has significantly informed the nature and focus of most counselling and support services within western health care settings.

Although sub-Saharan Africa is the geographical area with the highest incidence of HIV/AIDS in the world (Allen *et al* 2000), there is a dearth of research on the ways in which South Africans cope with the disease. However, in a study on this issue Stein (1996) obtained

meaningful findings which contradict the generally accepted beliefs about coping with HIV/AIDS.

In a qualitative study of 30 HIV positive patients at the Johannesburg General Hospital's HIV outpatient clinic, Stein (1996) found avoidant coping strategies did function as a protective buffer against negative HIV-related thoughts and concomitant feelings of hopelessness and helplessness. The results showed that what participants regarded as adaptive and beneficial coping was what, in the literature, is most commonly described as avoidant coping. By denying the reality of their HIV status, individuals created a space in which they could live their lives free of the burden of stigmatisation and social prejudice. By implication these individuals were rebelling against the social construction of an HIV-positive identity, and on a cognitive level they refused to succumb to the disease.

In connection with Stein's (1996) research, the coping models of Hobfoll (1998) and Holahan *et al* (1996) are of relevance. These authors emphasise the importance of the availability of adequate resources (such as social support and financial or material resources) as a determining factor in the selection of a coping strategy as well as in the outcome of the coping process. Since Stein's sample comprised general hospital outpatients of whom 72% were Black and 64% were women, it is highly probable that most of them were socio-economically disadvantaged persons who lacked the essential material, financial and other resources. This may have played a role in their selection of an avoidant coping style. However, because Stein did not supply information about the circumstances of her sample, this must remain mere conjecture. It is highly recommended that future South African research among similar sample groups examine the effect of circumstances on the coping styles and concomitant psychological well-being of HIV/AIDS patients.

What is more, Stein (1996) did not mention what stages of the disease the members of her sample group were in, except that they were asymptomatic at the time of the study. It would be useful if future South African research examined whether avoidant coping is employed mainly during the initial stages of the disease and whether coping styles become more active as the disease progresses, as found by Moneyham *et al* (1998).

Despite the limited scope of Stein's (1996) study, her findings challenge generally accepted notions concerning desired coping styles. Stein points out that, within a western medical model, problem-focused or active coping is undoubtedly the desirable response to an HIV diagnosis. It suggests a willingness to confront, process and accept the diagnosis and ultimately to continue with the business of living. In the African setting, however, where avoidance coping is seen as adaptive, the emphasis is not on the personal or individual process, but rather on the social and cultural context within which an individual functions. Stein's (1996) findings therefore challenge research-based beliefs about the relationship between coping styles and the quality of life in the majority of people living with HIV/AIDS in South Africa. Stein also points out that the relative efficacy of various forms of avoidance coping in relation to HIV/AIDS requires further investigation. In particular, a conceptual distinction needs to be drawn between avoidance strategies which imply denial and those which do not (Stein 1996: 68).

4. Conclusion

With regard to HIV/AIDS research, the South African context is a particularly challenging field due to the complex interplay between HIV/AIDS and socio-economic factors such as poverty, illiteracy, the migrant labour system, the lack of formal education, the low status of women, stigmatisation and discrimination (Allen *et al* 2000). All these factors, especially when simultaneous, compound the stress experienced by many HIV-positive people in South Africa and affect their coping styles.

In analysing the coping styles commonly employed by HIV-positive South Africans, as well as the demands, potentialities and restrictions of their social contexts, it is evident that these notions require careful review. Commonly held beliefs about the utility and desirability of specific coping styles need to be reconsidered. A clearer understanding of what it means for African patients to "cope" with HIV status would enable counsellors and healthcare workers to develop intervention strategies to meet the demands of their patients within a predominantly non-western socio-cultural context.

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