The subjective experience of being HIV-positive: Needs, strengths and coping strategies

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SUMMARY

THE SUBJECTIVE EXPERIENCE OF BEING HIV-POSITIVE: NEEDS, STRENGTHS AND COPING STRATEGIES

Keywords: HIV/AIDS, quality of life, health, psychological well-being, meaning construction, needs, strengths, coping strategies.

Adequate assessment of the needs of HIV-positive individuals in the South African context is essential, as it may provide insight concerning limitations in healthcare. This study focuses on the subjective experience of nine HIV-positive individuals, in order (a) to investigate their needs; (b) to gain knowledge and understanding of the strengths available to them; (c) to investigate their coping strategies; and (d) to generate a set of guidelines for the development of a secondary prevention programme to improve their psychological well-being and immune functioning. This article employs a qualitative research method, utilising hermeneutic thematic analysis to gain a greater understanding of the subjective psychological functioning of HIV-positive individuals in the South African multicultural context. To a great extent, this research focuses on the salutogenic/fortigenic perspective, where the focus is on strengths, capacities and emotional/psychological well-being.

Semi-structured interviews were conducted with nine asymptomatic HIV-positive individuals. The needs identified during this study involved the psychological, economical, informational and social categories.

The strengths available to HIV-positive individuals in order to make sense or construct meaning in their lives, consisted of four themes, namely internal, social, self-regulative and spiritual strengths. The study further indicates that the psychological strengths utilised by HIV-positive individuals are closely related to the concept of meaningfulness, the mechanisms of coping and psychological resilience.

A broad range of coping strategies was identified that participants employed in the management of the disease and in dealing with the negative emotions associated with an HIV-positive diagnosis. These strategies could be conceptually grouped into five categories based on the functions these strategies served, namely self-management coping strategies, cognitive coping strategies, social support coping strategies, religious coping strategies, and avoidance coping strategies.

The implications of this study are that the various identified concepts related to needs, strengths and coping strategies, may contribute to the development of a secondary prevention programme, in order to improve HIV-positive individuals' psychological well-being and immune functioning. The concept of "Sense of Coherence" which consists of three elements, namely Comprehensibility, Manageability and Meaningfulness, could be successfully incorporated into an intervention programme in order to achieve a positive redefinition of participants' subjective feeling that life is meaningful, as well as to improve their comprehensibility and manageability of their illness.

OPSOMMING

DIE SUBJEKTIEWE BELEWENIS VAN MIV-POSITIWITEIT: BEHOEFTES, STERKTES EN COPINGSTRATEGIEë

Sleutelterme: MIV/VIGS, lewenskwaliteit, gesondheid, psigologiese welsyn, betekenisvolheid, behoeftes, sterktes, copingstrategieë

Toereikende evaluering van die behoeftes van MIV-positiewe individue in die Suid-Afrikaanse konteks is noodsaaklik, aangesien dit insig kan bied in die beperkinge ten opsigte van gesondheidsorg. Hierdie studie fokus op die subjektiewe ervaring van nege MIV-positiewe individue, ten einde (a) hulle behoeftes te ontleed; (b) kennis en begrip in te win rakende die sterktes tot hulle beskikking; (c) om hulle copingstrategieë te ondersoek en (d) om 'n stel riglyne te genereer vir die ontwikkeling van 'n sekondêre voorkomingsprogram om hulle psigologiese welstand en immuniteitsfunksionering te verbeter. Hierdie artikel maak gebruik van 'n kwalitatiewe ondersoekmetode, deur hermeneutiese tematiese ontleding te gebruik om 'n beter begrip te verkry van die subjektiewe psigologiese funksionering van MIV-positiewe individue in die Suid-Afrikaanse multikulturele konteks. Hierdie navorsing fokus tot 'n groot mate op die salutogeniese/fortigeniese perspektief, waar die fokus op sterktes, kapasiteite en emosionele/psigologiese welstand is.

Semi-gestruktureerde onderhoude is gevoer met nege asimptomatiese MIV-positiewe individue. Die behoeftes wat in hierdie studie geïdentifiseer is, behels psigologiese, ekonomiese, informasionele en sosiale kategorieë.

Die sterktes wat tot die beskikking is van MIV-positiewe individue om sin te maak van of betekenis te konstrueer in hulle lewens het vier temas behels, naamlik interne, sosiale, selfregulerende en geestelike sterktes. Die studie het voorts aangetoon dat die psigologiese sterktes wat deur MIV-positiewe individue benut word nou ooreenstem met die konsep van betekenisvolheid, copingmeganismes en psigologiese veerkragtigheid.

'n Wye reeks copingstrategieë wat deelnemers gebruik in hulle bestuur van die siekte en in hulle hantering van die negatiewe emosies wat met 'n MIV-positiewe diagnose gepaard gaan, is geïdentifiseer. Hierdie strategieë kan konseptueel in vyf kategorieë gegroepeer word, gegrond op die funksies wat die strategieë vervul: copingstrategieë rakende selfbestuur, kognitiewe copingstrategieë, sosiale ondersteuningscopingstrategieë, religieuse copingstrategieë en vermydingscopingstrategieë.

Die implikasies van hierdie studie is dat die verskillende konsepte wat geïdentifiseer is om verband te hou met behoeftes, sterktes en copingstrategieë, 'n bydrae kan maak tot die ontwikkeling van 'n sekondêre voorkomingsprgram, ten einde MIV-positiewe individue se psigologiese welstand en immuniteitsfunksionering te verbeter. Die konsep van koherensiesin ("Sense of Coherence"), wat bestaan uit drie elemente, naamlik verstaanbaarheid, bestuurbaarheid en betekenisvolheid, kan met sukses in 'n intervensieprogram geïnkorporeer word om te lei tot 'n positiewe herdefinisie van deelnemers se subjektiewe gevoel dat die lewe betekenis het, en ook om hulle begrip en bestuur van hulle siekte te verbeter.

LETTER OF CONSENT

I, the co-author, K. F .H. Botha, hereby declare that the input and effort of Miss Susan Doubell is of sufficient scope to be a reflection of her work. I hereby provide consent that she may submit this manuscript in article format for examination purposes in partial fulfillment of the requirements for the degree Magister Scientiae in Clinical Psychology.

Dr. K. F. H. Botha

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MANUSCRIPT

The subjective experience of being HIV-positive: Needs, strengths and coping strategies

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Abstract

South Africa has an exceptionally high HIV prevalence rate of an estimated 11.4% or 4.74 million people living with HIV in 2001. Hermeneutic thematic analysis was utilised in gaining a greater understanding of the subjective psychological functioning of a group of HIV-positive individuals. The aims were to focus on the following aspects of HIV-positive individuals: (a) needs; (b) strengths; (c) coping strategies; and (d) to compile guidelines for the development of a secondary prevention programme to improve psychological well-being and immune functioning. Semi-structured interviews were conducted with nine asymptomatic HIV-positive individuals. The participants had various unfulfilled needs, including the need for professional counselling and therapy. However, they were able to apply certain strengths which enabled them to withstand and overcome intense personal demands and high levels of stress associated with HIV. Coping strategies were characterised by skills such as self-management and social interaction. Guidelines were provided for the development of a secondary prevention programme based on the salutogenic/fortigenic perspective.

Keywords: HIV/AIDS; quality of life; health; psychological well-being; meaning construction; needs; strengths; coping strategies.

The subjective experience of being HIV-positive: Needs, strengths and coping strategies

Human Immunodeficiency Virus (HIV) has become a chronic disease rather than a rapidly fatal illness, due to earlier detection as well as to improved prophylaxis and pharmacotherapy. A person is said to be HIV-positive when HIV antibodies are detected in his/her blood. To define AIDS (Acquired Immune Deficiency Syndrome) is, however, more difficult. Individuals are regarded as having AIDS when their CD4 cell count falls below 200 cells per cubic millimetre (Bartlett & Gallant, 2001), in correlation with a very high (above 30 000 copies/ml) viral load (Evian, 2000).

The South African Department of Health (Avert, 2003) has estimated that in 2001, 2.65 million women and 2.09 million men between the ages of 15 to 49 in South Africa were living with HIV. Estimates based on the most recent available data on the worldwide incidence rate of HIV/AIDS-related infections indicate 42 million people living with HIV/AIDS (UNAIDS, 2003; WHO, 2003). These high prevalence rates indicate the significance of the problem of HIV/AIDS, especially in South Africa. The rates also indicate the future burden of HIV-associated diseases and the difficulties faced by the health system in coping with the provision of adequate care and support.

No cure for HIV-infection has been found and although treatment alleviates some of the associated symptomatology, it has not been shown consistently to prolong life (Copfer et al., 1996). As a result of highly active antiretroviral therapy, the survival trajectory for people living with HIV (PLWH) has been extended, resulting in the transition of HIV from a debilitating terminal illness to a more manageable chronic illness (Rotheram-Borus et al., 2001; Schneiderman, Antoni, & Ironson, 1997). Medication can, however, never take away the traumatic element of an HIV diagnosis and its impact on the individual's self. The symptomatic HIV infection prior to the development of AIDS, is characterised by an atmosphere of extreme uncertainty and anticipatory anxiety, which may be more difficult to deal with than full-blown AIDS (Antoni & Schneiderman, 1998; Holt et al., 1998). Several studies corroborate the finding that the uncertainty surrounding the progression of HIV disease in conjunction with the knowledge that it is fatal, is a significant factor influencing the individual's psychological state of well-being (Govoni, 1988; Carlisle, 1994; Firn & Norman, 1995).

Emotional distress influencing the psychological well-being of PLWH, includes anguish, anxiety, worries, hopelessness, powerlessness, self-blame and despair (Cruess et al., 2000; Lee, Cohen, Hadley, & Goodwin, 1999; Nilsson Schönnesson & Ross 1999; Venier, Ross, & Akande, 1998). Furthermore, feelings of guilt, anger, life threat, shame and an increasing sense of responsibility to make immediate life changes may be experienced (Antoni & Schneiderman, 1998; Schneiderman et al., 1997; Antoni et al., 2000). Disruptions in close relationships, social marginalisation, and loss of work may place additional burdens on PLWH (Leary & Schreindorfer, 1998; Stevens & Tighe Doerr, 1997), thereby possibly contributing to disruptions in the psychological well-being of the individual.

PLWH in rural areas, which is often the case in South Africa, may face greater stigmatation than their urban counterparts, which could possibly result in a reluctance to disclose their HIV-status, and less social support (Heckman, Somlai, Kalichman, Franzoi, & Kelly, 1998; McCoy, Metsch, McCoy, & Weatherby, 1999). PLWH may fear a solitary life in terms of being abandoned and isolated, thereby creating a sense of being invisible. These emotions have an existential quality in that they represent a sense of being no-one, i.e. to experience psychological death (Igreja et al., 2000; Nilsson Schönnesson & Ross, 1999). Given the fact that HIV-infection results in AIDS, quality-of-life issues become more salient (Cowdery & Pesa, 2002; Onwumere, Holttum, & Hirst, 2002). HIV/AIDS-related stressors may therefore have a profound effect on the quality of life of PLWH, since these stressors affect the perception of well-being, independence, self-esteem, social relationships, and the energy reserves required to cope with the illness (Sowell et al., 1997).

HIV-related stressors may pose a serious challenge to the integrity of an HIV-infected individual's sense of self. PLWH might feel that the disease is in control of their lives. The physical symptoms and the psychological stresses that PLWH must confront have prompted research to focus on psychological distress. Because of this focus point, less is known about the levels of well-being among HIV-infected individuals. Emotional well-being among PLWH appears to be worse than for people with several chronic diseases (Hays et al., 2000). However, high levels of psychological distress that are usually associated with an HIV-positive diagnosis, do not necessarily imply the absence of positive affect. Individuals with chronic illness are able to adjust psychologically, and maintain or improve their levels of well-being and the quality of their lives (Igreja et al., 2000). According to Safren, Radomsky, Orro, and Salomon (2002) attributions about HIV, social support, and coping styles would explain more variance in psychological well-being than stressful life events per se. Long-term AIDS survivors are able to re-prioritise their lives and goals, have a positive attitude, derive satisfaction from helping others with HIV/AIDS and do not make AIDS the sole focus of their lives (Barosso, 1997).

Adequate assessment of the needs of PLWH in the South African context is therefore essential, as it may provide insight concerning limitations in healthcare. Needs are often unmet, partially met or narrowly defined, with the consequence that areas important to the lives of PLWH are excluded (Molassiotis, Callaghan, Twinn, & Lam, 2001). According to Bunting, Bevier and Baker (1999), the largest percentage of needs identified by poor women living with HIV in the United States involved psychological needs, in particular the need for support groups. A diversity of needs concerning physical aspects, information, household issues, spirituality, and legal and financial aspects were expressed (Bunting et al., 1999). Limited data on the specific needs of HIV-positive individuals in the South African context is available, which contributes to the necessity of this study.

Simoni and Cooperman (2000), found that strengths like high levels of spirituality, mastery and HIV-related support were generally associated with less depressive symptomatology and better physical well-being in PLWH. Meaningfulness and life purpose might be questioned by PLWH (Igreja et al., 2000). Positive responses to HIV-related stressors, specifically the discovery of meaning, may be linked to positive immunologic and health outcomes. The meaning that PLWH construct in their lives, as well as the way they interpret this traumatic event, is critical to the impact of HIV on psychological well-being (Muller, 1999). Meaningfulness is experienced when certain stimuli are perceived as motivationally relevant, in the form of welcome challenges which are worth engaging in, and investing oneself in (Strümpfer, 2003).

Clement and Nilsson Schönnesson (1998) conducted research on aspects such as coping styles and psychological functioning. One of the hypotheses made was that coping styles are associated with psychological functioning. More specifically, avoidant coping style is associated with poor psychological functioning, whereas active self-encouraging coping style is associated with good psychological functioning. The behavioural and cognitive aspects of avoidance coping (avoidance/wishful thinking, and social and emotional withdrawal) are closely associated with depressive mood symptoms, lower levels of energy and social functioning (Clement & Nilsson Schönnesson, 1998; Vosvick et al., 2003). According to Lutgendorf et al. (1998) enhanced coping skills, and increased use of active coping (including seeking support, spirituality, and managing the illness), may enable PLWH to make better use of social support, or may result in social support enhancing coping skills. PLWH who employed effective coping strategies in dealing with the disease, experienced less mood disturbances and psychological distress (Segerstrom, Taylor, Kemeny, & Fahey, 1998).

According to Vosvick et al. (2003) the development of adaptive coping strategies may improve the functional aspects of quality of life in PLWH. Quality of life plays a crucial role in influencing positive health behaviours, reducing or eliminating risk behaviours and maintaining motivation (Lawton, 1999). In a clinical setting, the definition of quality of life is limited to those aspects of life directly affected by health status and is often referred to as health-related quality of life (Franchi & Wenzel, 1998). This health-related approach to 'quality of life', however, does not acknowledge the individual's subjective experience of well-being independent of health status. It often relies on the researcher's assessment and interpretation of quality of life.

Increasing evidence shows that psychological stressors can possibly lead to changes in an individual's immune system, and appears to modulate patterns of leucocyte trafficking, T-cell blastogenesis and natural killer cell cytotoxicity (Miller, Dopp, Myers, Stevens, & Fahey, 1999). In a follow-up study Moneyham et al. (1998) found that active coping predicted a reduction in physical symptoms three months later. Although this focus area needs more intensive research, it seems as though positive behaviour, emotions and thoughts can enhance immune function, and thereby possibly alter the course of diseases of immunity, such as HIV/AIDS (Cruess et al., 2000; Leserman et al., 2000; Lutgendorf et al., 1997; McEwen, 1998; Molassiotis et al., 2002; Moore et al., 1998).

Previous research mainly applied quantitative research methods, generating data by means of standardised instruments (Banyard & Miller, 1998; Trickett, 1984). The subjective experience of PLWH in South Africa is still unclear, especially from a qualitative research perspective. Qualitative inquiries contextualise health and illness in concrete circumstances instead of decontextualising them in abstract and general cognitive models (Flick, 2000). Quantitative analysis is clearly important, in that it has provided effective medications, multiple treatments, and the identification of HIV, but it neglects the lived experiences and views of those living in adverse life circumstances (Hodgetts & Chamberlain, 2000; Krycka, 1997). The meanings that people assign to their circumstances are an important consideration for health psychologists who attempt to develop an understanding of the relationship between coping strategies and illness (Hodgetts & Chamberlain, 2000).

Various researchers focus on primary and tertiary prevention. The findings from this research can be successfully utilised by psychotherapists and HIV counsellors as guidelines to compile a secondary prevention programme, aimed at improving the quality of life and immune function of PLWH. To compile such a programme, it is essential to focus on the needs of PLWH in the South African context.

The aims of this study therefore were:

(a) to explore the subjective needs experienced by PLWH;

(b) to explore the subjective strengths available to PLWH;

(c) to explore the subjective coping strategies experienced by PLWH; and a DSM IV Axis I or II disorder (American Psychiatric Association, 1995), and (c) insufficient mental ability to participate.

Procedure

Participants were identified through the National Association of People living with AIDS in South Africa (NAPWA). Individual semi-structured interviews were conducted in privacy at the counselling institutions where the participants were recruited. Each interview lasted approximately 45 minutes. The standard question asked was "Tell me the story of your life as an HIV-positive individual and how you make sense of it." Follow-on questions or facilitative comments were made after completion of the participant's story, to ensure clarity of the narratives (e.g. "please explain further … ") and to obtain information specifically on aims 1, 2 and 3, i.e. their needs, strengths and coping strategies. The interviews were audio-recorded as it allowed the researcher to give participants full and undivided attention [cf. Rubin and Babbie (1998)].

Ethical considerations

To ensure that ethical aspects were not violated, verbal and written information about the research was given to the participants to obtain informed consent. The following were focused on: (a) a full explanation about the research was given, (b) the anonymity and confidentiality of the participants were preserved, and (c) as sensitive issues discussed during the research may have triggered psychological distress, resources were available to participants in case follow-up was needed, and participants also had the option to withdraw from the research at any time.

Analysis

The method of analysis used was hermeneutic thematic analysis. The aim of hermeneutics, according to Wilson and Hutchinson (1991, p.266) is "to discover meaning and to achieve understanding" or to make sense of "that which is not yet understood", as described by Addison (1992, p.110).

This method does not consist of a set of prescribed techniques (Addison, 1992). The approach followed in this study was adapted from the practices suggested by Addison (1992) and Wilson and Hutchinson (1991), and included the following steps:

Step 1: Interviews were audio-recorded and transcribed verbatim for analysis.
Step 2: The researcher listened to the tape recordings while simultaneously reading the transcribed interviews. The information from each tape was reduced into units of meaning. A summary was formulated from these natural-meaning units. The summaries of all the interviews of each of the participants formed the participant's biography as recounted by the researcher.
Step 3: The researcher reread the original transcriptions, and elicited patterns and themes, descriptions or categories which are relevant to the research context – i.e., to the context of the HIV-positive individual's needs, the availability of strengths in order to construct meaning in their lives, and coping strategies. This information represented the HIV-positive individual's story.

Step 4: The researcher processed these stories into a description portraying the recurring themes that emerged from the stories of the participants. General themes emerged that subsumed other themes, but were nonetheless idiosyncratic and context-specific. Other themes seemed more pertinent to an individual participant.

The supervisor of this research project, a registered psychologist, acted as co-analyst to ensure valid and reliable results.

RESULTS

According to the aims of this research, the subjective needs, strengths and coping strategies of PLWH were identified. Although strengths and coping strategies are closely related, these aspects were seperately explored and discussed due to the fact that strengths were experienced as a subjective feeling by PLWH, whereas coping stategies were experienced as observable actions. The guidelines for the development of a secondary prevention programme to improve psychological well-being and immune functioning are presented in the discussion.

Needs

The needs identified involved the categories as shown in Table 1, namely psychological, economical, informational and social.

Table 1. Needs of HIV-positive individuals (refer to Addendum 1)

The psychological need most reported was that of (a) professional counselling and therapy to support those affected to deal with the HIV-positive diagnosis and to deal with other individuals affected by HIV and AIDS, as well as the need to ventilate about issues surrounding death, such as unfinished business, acceptance, coping and information. One participant, for example, explained this need as follows:

> *I think my difficulty right now is that because I am this kind of person that I am, it's very difficult to find people who I can confide in. So in terms of my own psychological needs, I find it difficult to find the right people to talk to. I wish I could have such a session once a month, where I'm just talking, and someone guides me through my pain and sorrows. Or things that I experience on a daily basis.*

Other themes of psychological needs include needs for (b) longevity, and (c) optimal quality of life.

Economical needs include financial security needs identified through (a) needs for job opportunities, and (b) financial assistance. The need for financial assistance was emphasised by most of the participants, which was evident through this comment made by a participant:

> *But unfortunately the finances. We don't have the finances.*

Examples of ***information needs*** include needs for knowledge and education, further specified through (a) needs for accurate information and education about HIV/AIDS and (b) needs for public awareness about HIV/AIDS as expressed by a participant:

> *I want to learn more and more about this disease. My daughters included. I want them to know what is happening to me.*

Social needs include the need for support, love and understanding and was characterised by the need for assurance that family members will be taken care of when the participants reach the AIDS stage, as experienced, for example, by one participant:

> *Ja, and if only I can get somebody who I can trust, who can look after my daughters, I don't know who.*

Social needs also include the need to find a compatible life partner as well as the ability to honestly disclose their HIV status.

Strengths

The strengths available to PLWH in order to make sense or construct meaning in their lives (Table 2), consist of the following themes, namely internal strengths, social strengths, and spiritual strengths.

Table 2. Strengths of HIV-positive individuals (refer to Addendum 2)

The concept of internal strengths consists of four themes, namely cognitive strengths, conative strengths, emotional strengths and self-regulative strengths. Cognitive strengths include: (a) the ability to be optimistic and to have hope, and (b) acceptance of the HIV-positive diagnosis, including participants' acceptance of themselves and personal weaknesses. The cognitive theme of optimism were emphasised by the following explanation:

> *I try to stay positive, I'm always positive, always, whatever I do, I don't regard myself as HIV-positive, although the results show I'm HIV. Myself I mean, with the treatment that I'm taking, I'm going forward, I'm going forward. Always positive, always.*

Conative strengths include (a) the concept of determination, (b) the ability to gain inspiration from others, and (c) assertiveness. Emotional strengths include (a) being proud, as well as (b) having courage. Self-regulation as an internal strength include themes of (a) control, (b) proactive behaviour, and (c) self-meaning. The experience of self-control as strength is illustrated by the following:

> *This is your life. You're the one who have to control it, you have to take charge of your life ... it's up to you whether you want to live or you want to be a sick person.*

Experiencing self-meaning as strength, a participant, for example, remarked the following:

> *It's what you make out of it. If you want it to be a failure, life will be a failure for you. If you want it to be a success, life will be a success. As long as you are on the right track.*

Social strengths include themes of interpersonal skills, forgiveness and social meaning. Interpersonal skills consist of theme dimensions such as (a) the ability to form close relationships and (b) the ability to reach out to individuals in need, for example:

> *And seeing other person, I've got a lot of persons I see, and when they come back some time and say hey, I'm feeling great and I'm getting well, and I see an improvement, I'm like ooh, this is my achievement!*

Forgiveness as a strength consists of participants' ability to forgive the individuals who transmitted the HI-virus, and therefore caused their HIV-infection. Social interaction as a way to construct social meaning was particularly well illustrated by statements like:

> *Helping people. I wake up in the day for somebody else.*

Spiritual strengths are the final category of strengths and include themes of spiritual beliefs and spiritual meaning. Participants reported that the ability to maintain faith in spite of being diagnosed as HIV-positive, was considered as a personal strength. One participant, for example, experienced spiritual beliefs as follows:

> *... and when I am tired and weary, I just draw my strength from the Bible.*

Making sense of illness through spirituality was explained by statements like :

> *God doesn't bring people just for nothing. He's got a purpose for everything.*

Coping strategies

A broad range of coping strategies employed by participants to deal with negative emotions associated with an HIV-positive diagnosis, as well as to manage the disease, were identified. These strategies could be conceptually grouped into five categories, based on the functions these strategies served (Table 3), namely self-management, cognitive, social support, religious, and avoidance.

Table 3. Coping strategies of HIV-positive individuals (refer to Addendum 3)

Self-management coping strategies include the following themes: (a) lifestyle and illness management, characterised by dimensions like making changes in diet, (b) future orientation, and (c) job management. The experience of one participant, for example, in terms of coping through lifestyle management, was voiced as:

> *And also in terms of lifestyle. I've always lived kind of a healthy life, but not as much as I do now. I mean I don't just eat anything. I don't drink anything. I'm very fussy, because that's how I have to nurture my body, as an individual to be able to cope with my situation.*

Cognitive coping strategies consist of (a) cognitive control and (b) acceptance. A participant experienced the following regarding cognitive control, in terms of responsibility and self-control:

> *And since then, I started, it made a whole lot of sense that it's you that's gonna do something, that's all these people around me always have ... It's you that's have to do something.*

One participant, for example, further explained the coping strategy of acceptance of weaknesses:

> *But I allow myself to break. Cause where there's pain, you can't pretend. I'm not the great pretender.*

Social support coping strategies include (a) disclosure and venting of emotions through family, friends and professionals, as well as (b) inspiration gained through interaction with others and humour. Humour was used during the interviews by various participants, although only one specifically named it as a coping strategy. Disclosure and venting of emotions was characterised by statements like:

> *Because I believe talking is healing, and the more I talk, the more I heal myself. And that's how.*

Religious coping strategies consist of beliefs and practices, such as prayer participation. Some of the participants drew comfort from the belief that God or an omnipotent being would guide them to meet the stresses and demands of the illness, as experienced. A participant made the following remark in this regard:

> *But I prayed and prayed and prayed. Spiritually I'm fulfilled. Again, this is another coping mechanism that I have used.*

Avoidance coping strategies include themes of (a) mental avoidance and (b) social avoidance. Although these behaviours were not especially purposeful, their "automatic, survival mode" quality helped some participants cope during the time following the diagnosis. Mental avoidance as a coping strategy was experienced as follows by a participant:

> *I think I have this problem, this tendency, I always push things aside. It's kind of like it's not completely blocked in my mind, but then I choose not to worry about it. I say always to myself, the time for me to worry about it is not here. I think I'll start dealing with it maybe when I become sick.*

DISCUSSION

The aims of this article were (a) to explore the subjective needs experienced by PLWH, (b) to gain knowledge and understanding of the subjective strengths available to PLWH, (c) to explore the subjective coping strategies experienced by PLWH, and (d) to generate a set of guidelines for the development of a secondary prevention programme to improve the psychological well-being and immune functioning of PLWH.

Participants experienced various needs, in particular to receive professional support, as well as to maintain quality of life. To a lesser extent, needs concerning financial stability, information and family support were experienced. However, a surprisingly number of strengths were experienced, mostly internally localised, supported through social and spiritual strengths, and applied through self-regulation. In addition to strengths, a broad range of coping strategies was employed. The majority of these strategies seemed to be constructive, although avoidance strategies were additionally used to a lesser extent. According to these findings, it seems as though the participants' subjective experience of being HIV-positive included a considerable amount of positive aspects, which could be successfully utilised in counselling and intervention programmes.

Psychological needs appeared to be the primary concern of PLWH in managing life-threatening stressors, in correspondence with the findings of Bunting et al. (1999). Participants experienced a strong need for professional counselling and therapy, particularly regarding the ventilating of issues surrounding death, and skills to accept and manage the illness in the AIDS stage, similar to the findings of Burnard (1993). This possibly led to the need for longevity and quality of life. The emphasis on psychological needs, may be explained by the fact that most of the participants were recruited through NAPWA and other HIV/AIDS counselling organisations, where they are actively involved in the issues pertaining to their disease. Participants' involvement with AIDS patients in support groups creates a constant awareness of the possibility to contract opportunistic infections, possibly resulting in AIDS and consequently death, which could have triggered these intense psychological needs.

In spite of the fact that many participants used information-seeking as a coping strategy to facilitate preparation for their future, various participants expressed the need for more knowledge and education about HIV/AIDS, consistent with the findings of Walker (2002). This may be due to unavailability of information in certain regional areas, as well as challenging financial circumstances, contributing to the lack of informational resources. The need experienced for information and knowledge may enable the individual to exercise self-determination (Nichols, 1985), described as a conative internal strength in this study. Financial dependence as well as financial constraints seems to be a common factor concerning needs, and possibly seems most likely for chronic, progressive and expensive diseases such as HIV. Being diagnosed as HIV-positive may preclude employment and pose the threat of loss of life insurance (Burnard, 1993; Jenkins & Guarnaccia, 2003). Social needs are prevalent in PLWH, in particular the need for support, love and understanding, similar to needs reported in a study regarding emotional support needs (Jorgensen & Marwit, 2001). This corresponds with the findings of Walker (2002), who noted that supportive networks are crucial to cope with a multitude of stressors.

The use of cognition as an internal strength corresponds with the findings of Walker (2002), indicating the use of optimism and a sense of hope as a source of resilience. It is further noteworthy that the findings regarding courage, experienced as an emotional strength in this study, are similar to the findings of Walker (2002), who reported that fear of stigmatisation may lower resilience in PLWH. The perceived self-control reported by the participants as a self-regulative strength may suggest that these individuals recognise their ability to control some aspects of their illness (e.g. symptoms) and healthcare. This corresponds with the findings of Simoni and Cooperman (2000), identifying mastery as a considerable strength.

Social strengths identified in this study, may be a factor influencing the ability to employ social coping strategies, since participants viewed interpersonal skills such as the ability to form close relationships as a social strength. According to Simoni and Cooperman (2000), HIV-related social support as a strength generally correlated with improved psychological and physical adaptation. Furthermore, participants constructed social meaning in their lives through social interaction. It is possible that a connection exists between turning to the spiritual dimension and the attempt to find meaning in life, as well as an effective coping style (Burke & Miller, 1996). Spiritual meaning possibly provided the path that led to hope for the participants, not necessarily in finding a cure for HIV/AIDS, but in obtaining the means of living a positive life. Similar to the findings of Simoni and Cooperman (2000), spiritual beliefs were considered as a strength, which could possibly have led to the utilisation of religion as a coping strategy.

Religious coping strategies were identified as a separate coping factor, which may reflect the great emphasis on religiosity or the strong role played by religious service organisations. Kaplan, Marks, and Mertens (1997) discovered that prayer was a frequent coping response in woman with HIV/AIDS. Given the belief in a power greater than oneself by many PLWH, there may be untapped opportunities for intervention by healthcare professionals in this arena. PLWH who engage in active self-management coping strategies, such as lifestyle and illness management or seeking out treatment-related information (future orientation), have been shown to report higher quality of life (Friedland & Renwick, 1996). Leserman, Perkins and Evans (1992) note the use of coping strategies in asymptomatic PLWH, including planning a course of action, which are similar to future orientation as a self-management coping strategy in the present research. Taking control and responsibility, as well as the level of acceptance of the HIV-positive diagnosis and of personal weaknesses, a cognitive coping process, reflects a sense of empowerment. It involves changed attitudes and beliefs about individuals' ability to possibly alter their life course. The fact that the participants in this study seek the support of others in coping with HIV adds weight to an established body of literature (Leserman et al., 1992; Murphy, Mosciki, Vermund, Muenz, & The Adolescent Medicine HIV/AIDS Research Network, 2000; Nott, Vedhara, & Power, 1995), underscoring the connection between social support and positive adaptation in PLWH.

Avoidance coping is generally considered maladaptive (Roger, Jarvis, & Najarian, 1993). However, given that HIV constitutes a chronic and life-threatening stressor, a highly stigmatised disease, involving alternating symptomatic and asymptomatic phases, it would seem likely that different coping responses may be adaptive at different stages of HIV and AIDS. Negative or potentially maladaptive coping strategies, in particular avoidance, however, were not often experienced by the participants, though it was strongly experienced by four participants. While these coping strategies most likely are employed by most PLWH, the fact that the participants in this study at least had to acknowledge their status and be willing to disclose their experiences of living with the disease, may account for the low presence of these negative coping strategies in the findings.

Given the study's small sample size, the unequal representation of men and women as well as the focus on subjective experience, caution is warranted in generalising the results to a broader population. As with all HIV-related research, self-selection bias may be a particularly strong threat to the external validity of the findings. Given the strong stigma attached to the disease and the reluctance of many to disclose their infected status, even when confidentiality is assured, it is difficult to assess how participants in this study may differ from the larger population of infected individuals.

However, such estimates were not the goal of the present research (nor is it the goal of qualitative research in general). Rather, the aim was to generate insights into participants' needs, available strengths and coping strategies in order to suggest guidelines for the development of a secondary prevention programme to improve the psychological well-being and immune function of PLWH.

Although various intervention programmes have been designed for PLWH, the need exists for programmes aimed at the psychological well-being of PLWH, specifically in the South African context, which could enable them to deal with the impact of a positive diagnosis more effectively. Since a number of strengths and constructive coping strategies were identified in the current study, it could be appropriate to base an intervention programme on the salutogenic/fortigenic perspective, where the focus is on strengths, capacities and psychological well-being of PLWH. Antonovsky (1987) formulated the concept of "Sense of Coherence" (SOC), which consists of three elements namely Comprehensibility, Manageability and Meaningfulness. These aspects of SOC could be successfully incorporated into an intervention programme to promote participants' subjective experience that life is meaningful, as well as to improve the comprehensibility and manageability of their illness.

Since this particular study focused on the subjective experience of strengths and meaningfulness, and coping strategies in PLWH, these aspects should not be assumed to be necessarily effective in leading to long-term psychological adaptation and well-being. Subsequent research should examine the value of the strengths identified and the specific manner in which meaningfulness is achieved, as well as the effectiveness of the coping strategies for achieving psychological adjustment to the illness. The identified psychological strengths of meaningfulness could be utilised in an intervention programme to develop the ability of PLWH to create and maintain meaningfulness in negative situations. The identification of the various strengths and coping strategies in this study could possibly facilitate the successful management of stressors, and thereby contribute to SOC. There is accumulating evidence that SOC is associated with a general sense of psychological well-being (Carstens & Spangenberg, 1997). The needs reported in this study create the opportunity to identify and limit shortcomings in current intervention programmes. The practitioner facilitating change through an intervention programme needs to remain open to individuals' different responses to an HIV-positive diagnosis, and then to provide guidelines congruent with each HIV-positive individual's unique needs.

In conclusion, PLWH are faced with an array of psychological and other needs from the time of diagnosis, through a possible long and traumatic disease period. In order for PLWH to meet their needs, an exploration of their subjective, personal strengths is essential. Psychological strengths may contribute to the utilisation of coping strategies. As a result, PLWH may be able to construct meaning in their lives to live a quality life and facilitate psychological well-being.

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ADDENDUM 1

Table 1. Needs of HIV-positive individuals

1. Psychological needs	
Themes	***Theme dimensions***
Professional counselling and therapy	Guidance to develop coping skills regarding HIV The need to ventilate about issues surrounding death - unfinished business, acceptance, coping and information
Longevity	The need to have more time Concern for children's future
Quality of life	To live life optimally Continuing normality The need to conceive and raise children The need for self-satisfaction The need to live a lost life stage due to time of onset of HIV
2. Economical needs	
Themes	***Theme dimensions***
Financial security	The need for job opportunities The need for financial assistance in order to receive medication to maintain current state of health
3. Information needs	
Themes	***Theme dimensions***
Knowledge and education	The need for information about HIV/AIDS The need for information about HIV/AIDS to be given to others / needs for public awareness
4. Social needs	
Themes	***Theme dimensions***
Support, love and understanding	The need to know their family will be taken care of when they reach the AIDS stage The need to find a compatible life partner Ability to honestly disclose HIV diagnosis

ADDENDUM 2

Table 2. Strengths of HIV-positive individuals

1. Internal strengths	
Themes	***Theme dimensions***
Cognitive	Optimism / hope Acceptance (of self and HIV; of weaknesses and limitations) Self-knowledge Mental ability Independence
Conative	Determination (to find joy/happiness; to be hardworking) Inspiration Self-assurance / assertiveness
Emotional	Courage Pride
Self-regulative	Control Proactive behaviour Self-meaning
2. Social strengths	
Themes	***Theme dimensions***
Interpersonal strengths	Ability to form close relationships Ability to reach out to individuals in need To be a good listener / give good advice
Forgiveness	Ability to forgive the person who transmitted the HI-virus
Social meaning	Social interaction
3. Spiritual strengths	
Themes	***Theme dimensions***
Spiritual beliefs	Faith
Spiritual meaning	Appreciation of life Spiritual wellness - believing in a higher purpose

ADDENDUM 3

Table 3. Coping strategies of HIV-positive individuals

1. Self-management coping strategies	
Themes	***Theme dimensions***
Lifestyle and illness management	Making changes in diet Exercise Conducive environments Introspection through meditation Safe sex practises
Future orientation	Information seeking / Preparation and active involvement Goal-oriented / Planning for the future
Job management	Stay focussed on work Making the most of the present moment
2. Cognitive coping strategies	
Themes	***Theme dimensions***
Cognitive control	Responsibility and control over self Intellectual awareness Maintaining objectivity Optimism Visualization to gain control over uncertainty
Acceptance	Acceptance of diagnosis Acceptance of weaknesses or limitations
3. Social support coping strategies	
Themes	***Theme dimensions***
Disclosure and venting of emotions	Family and friends Professionals
Humor and inspiration	Inspiration from children Humor Inspiration gained through the knowledge of individuals surviving with HIV
4. Religious coping strategies	
Themes	***Theme dimensions***
Beliefs and practises	Prayer participation Faith Practising formal religious behaviours / rituals
5. Avoidance coping strategies	
Themes	***Theme dimensions***
Mental avoidance	Mental disengagement / Self-distraction techniques
Social avoidance	Isolation