

SELF-CARE SYMPTOM-MANAGEMENT STRATEGIES AMONGST WOMEN LIVING WITH HIV/AIDS IN AN URBAN AREA IN KWAZULU-NATAL

Authors:

Regis R. Marie Modeste¹
Sisana J. Majeke²

Affiliations:

¹School of Nursing,
University of the Western
Cape, South Africa

²School of Nursing,
University of KwaZulu-
Natal, South Africa

Correspondence to:

Regis Marie Modeste

email:

rmodeste@uwc.ac.za

Postal address:

Room G4, Senate Building,
School of Nursing,
University of the Western
Cape, Modderdam Road,
Bellville 7535, South Africa

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ABSTRACT

People living with HIV and AIDS experience a number of symptoms such as fatigue, nausea and vomiting, fever and anxiety during the various stages of the illness. This has a negative effect on their quality of life. Women are the most commonly infected group and are at greater risk of acquiring HIV than men. In addition to their vulnerability, women have other responsibilities in society and expectations from society to fulfil. Women's health-seeking and health practice behaviours are often hindered by a number of factors, including family responsibilities, poverty and fear.

This paper presents the findings of a qualitative study aimed at exploring the self-care symptom-management strategies used by women living with HIV and AIDS in an urban area in KwaZulu-Natal in 2006.

Eleven participants were selected through a purposive sampling method until saturation was reached. Individuals were assessed in depth, using the symptom-management strategy interview. Qualitative content analysis was used to examine the transcribed interviews, using a deductive approach based on the categories of self-care symptom-management strategies.

Various physical and psychological symptoms and a number of self-care symptom-management strategies were reported by the participants and these included taking medication and seeking help.

The study makes recommendations on how to improve women's ability to employ a self-care strategy in managing their HIV- and AIDS-related symptoms.

OPSOMMING

Mense wat met MIV en Vigs leef, ervaar verskeie simptome in die verskillende stadiums van die siekte, soos moegheid, naarheid en braking, koors en angstigheid. Dit het 'n negatiewe effek op hul lewensgehalte. Vroue is die groep wat die meeste besmet word, en staan 'n groter risiko om MIV op te doen as mans. Benewens hul vatbaarheid, het vroue ook ander verantwoordelikhede en verwagtinge om in die samelewing te vervul. Vroue se gesondheidsbevorderende en gesondheidspraktykgedrag word dikwels gekniehalter deur 'n aantal faktore, wat familieverantwoordelikhede, armoede en vrees insluit.

Hierdie artikel bied die bevindinge aan van 'n kwalitatiewe studie gemik op die verkenning van selfsorg-simptoombeheerstrategieë wat deur vroue met MIV en Vigs in 2006 in 'n stedelike gebied in KwaZulu-Natal gebruik is.

'n Steekproef van 11 respondente is geselekteer deur middel van 'n doelbewuste steekproefmetode totdat versadiging bereik is. Individuele diepte-onderhoude is gevoer deur gebruik te maak van die simptoombeheerstrategie-onderhoud. Kwalitatiewe inhoudelike analise is gebruik om die getranskribeerde onderhoude te analiseer deur middel van 'n deduktiewe metode gegrond op die kategorieë van selfsorg-simptoombeheerstrategieë.

Verskeie fisiese en psigologiese simptome asook 'n aantal selfsorg-simptoombeheerstrategieë is deur die respondente gerapporteer. Die selfsorg-simptoombeheerstrategieë wat in die studie identifiseer is, het die neem van medikasie en die soek na hulp ingesluit.

Die studie maak aanbevelings oor hoe om vroue se vermoë om 'n selfsorg-strategie om MIV- en Vigs-verwante simptome te beheer, te verbeter.

INTRODUCTION**Background**

It has been nearly three decades since the emergence of the human immunodeficiency virus (HIV), and the number of infected people continues to increase. In just 1 year (2007), approximately 33 million people worldwide were infected with HIV; 2.7 million people were newly infected, and approximately 2.0 million deaths from AIDS were documented (UNAIDS 2008:32). Sub-Saharan Africa is the region hardest hit by the epidemic, accounting for approximately 67% of all people living with HIV. South Africa has the highest number of people living with HIV in the world, at an estimated 5.7 million reported in 2007 (UNAIDS 2008:40).

In sub-Saharan Africa, nearly 60% of all people infected with HIV are female (UNAIDS 2008:33). South Africa shows similar trends and it is estimated that of the 5.27 million HIV-infected individuals aged 15 years and older, 2.8 million are female (Department of Health 2008:24). Figures such as these have been reported since the early 2000s by the Nelson Mandela and/or Health Science Research Council (HSRC)

study of HIV and AIDS carried out in 2002, as well as by the National HIV and Syphilis Antenatal Sero-prevalence Survey in South Africa, carried out in 2003 to 2005 (Department of Health 2003:1; Department of Health 2004:10; Department of Health 2006:17; Shisana & Simbayi 2002:45).

There are a number of different factors that contribute to the higher prevalence of HIV in women. A woman's biological make-up, for instance, predisposes her to HIV infection more than a man's biological make-up. Women have a large vaginal mucosal surface that is exposed, and during sexual intercourse they are usually the recipients of the infected seminal fluid (Pratt 1995:176). Other factors, economic, social and cultural, including gender and power inequalities, make women more vulnerable to HIV than men. Women are often dependent on men economically, socially and culturally, and this increases their vulnerability (Global HIV Prevention Working Group 2003:8). The high incidence of younger girls having sex with older men is another factor to be noted. Older men are more likely to have had more partners, and are more likely to be HIV-infected than younger men (Pratt 1995:177; Shisana & Simbayi 2002:58). Women lack not only the knowledge, but also the power to negotiate safer sexual practices, because not only will they possibly face violent reactions from their partners, but they also risk being abandoned by their partners and facing economic and social hardship (Global HIV Prevention Working Group 2004:13; UNAIDS 2004:68, UNAIDS/WHO 2004:4).

HIV was once considered a death sentence illness. It is now considered a chronic illness, and access to and the availability of antiretroviral (ARV) treatment have increased, with ARV coverage at 40.2% in 2008, compared to 4.9% in 2004 (Adam & Johnson 2009; UNAIDS 2008:33). Like other chronic illnesses, most of the care for HIV-infected patients is managed in the home and in the out-patient setting, making self-care a very important aspect of the management of HIV and AIDS (Chou & Holzemer 2004:58; Chou *et al.* 2004:332; Korff *et al.* 1997:1097). The management of HIV- and AIDS-related symptoms is achieved by means of professional care, as well as self-care.

Self-care involves all the activities performed by persons living with HIV and AIDS to enhance health, prevent diseases, manage symptoms and restore health. People can keep themselves healthy by adopting a healthy lifestyle. This is crucial because as the illness progresses, one is bound to experience an increase in symptoms (Chou *et al.* 2004:332). The self-care symptom-management system focuses on self-care activities directed at dealing with the experienced symptoms (Chou *et al.* 2004:335; Chou & Holzemer 2004:58). By practising evidence-based nursing, health care workers will have the knowledge to identify women's HIV- and AIDS-related symptoms and will be able to focus on advising them on their self-care symptom-management strategies.

Purpose of the study and research questions

The purpose of this study was to explore the self-care symptom-management strategies used by women living with HIV and AIDS in an urban area in the eThekweni district in KwaZulu-Natal. The research questions for the study were the following:

- *What are the self-care symptom-management strategies used by women living with HIV and AIDS and experiencing HIV- and AIDS-related symptoms?*
- *How are self-care symptom-management strategies practised by women experiencing HIV- and AIDS-related symptoms?*

Literature review

HIV- and AIDS-related symptoms

HIV has the unique ability to destroy the immune system by attaching to the CD4 cell surface receptor as a port to enter and infect the cell. The invading virus weakens the immune system and opens the door for opportunistic infections (Pratt 1995:64).

There is a wide range of opportunistic infections that affects people living with HIV and AIDS, and the effect on their quality of life varies, depending on the type and intensity of the symptoms experienced. The infected people are the best judges of symptoms, as it has been shown that often other people, including health professionals, underestimate the frequencies and intensity of symptoms (Holzemer 2002:49). There are symptoms that are experienced physically, such as fever and diarrhoea, whilst other, psychosocial manifestations include fear, anxiety and depression; both types of symptoms affect the quality of life of the people experiencing them (Holzemer 2002:49).

The importance of symptom management

Symptom experience is recurrent for people infected with HIV, and, as noted by Tsai, Hsiung and Holzemer (2002:301), symptoms may be due to the illness itself, or may be a side effect of the medication for those that have access to ARV medications. Previous studies have shown that symptoms have a negative impact on quality of life (Holzemer 2002:48; Holzemer *et al.* 1999:1043; Nicholas 2005:1).

With the increased availability of ARV medications, HIV infection is no longer a fatal, debilitating disease, but has become more of a chronic illness, and it has been noted that patients and their families are the primary caregivers in chronic illness (Hughes 2004:75; Hung *et al.* 2006:222; Korff *et al.* 1997:1097). This involvement is important for patients infected with HIV, because increasing patients' involvement in the management of their symptoms will improve their quality of life, supplement the medical care and reduce the overload in health services.

Self-care symptom-management strategies

Like any other chronic illness, self-care is an important aspect of symptom management of people living with HIV and AIDS (Chou *et al.* 2004:332). Self-care symptom-management strategies are those activities adopted by the patients to manage their health problems. Multiple types of self-care strategies have been documented as used by patients living with HIV and AIDS in the management of HIV- and AIDS-related symptoms, and it has been reported that most patients are aware of some of these strategies (Chou 2004:110; Chou *et al.*, 2004:336; Holzemer, 2002:50).

Women are more at risk of HIV infections. Their self-care management is very important, and steps should be taken to strengthen this management, because for many women it is the first or only approach to dealing with their HIV- and AIDS-related symptoms (Nicholas 2005: 5).

Because South Africa has been documented as the country with the highest number of people living with HIV and AIDS in the world, health care workers need to be familiar with the strategies used by women living with HIV and AIDS in their self-care symptom management.

RESEARCH METHOD AND DESIGN

Methodology

This was a descriptive, exploratory study, and a qualitative approach was adopted. The population studied was women living with HIV and AIDS who were experiencing HIV- and AIDS-related symptoms and the research was conducted in an urban area of the eThekweni district in KwaZulu-Natal at the Sinikithemba HIV and AIDS care centre. The centre comprises three linked programmes, which are the Sinikithemba clinic, the Sinikithemba training programme and the Sinikithemba development programme (Giddy 2005:3). The participants were recruited by the researcher from the Hope House, a branch of the Sinikithemba clinic which provides voluntary counselling and testing services, CD4 testing, psychosocial assessment and psycho-social-spiritual support.



Data were collected from a sample of 11 participants until data saturation was reached and new themes were no longer arising from the interviews. The respondents were selected through purposive sampling, a method used to choose individuals that have characteristics of the population in question or are particularly knowledgeable about the issues under study (Polit & Hungler 1999:284).

Maximum variation was obtained by sampling respondents within a range of ages, varying from 25 to 57 years. The women were screened using the Revised Sign and Symptom Check-List for Persons with HIV Disease (SSC-HIVrev) instrument to establish the presence of HIV-related symptoms experienced by them (Holzemer *et al.* 2001:68). Individual, in-depth interviews were conducted in English using the symptom-management strategy interview guide adopted from Bunch (2004:169).

Data analysis

The interviews were transcribed verbatim by the researcher, after which qualitative, conceptual content analysis was conducted, using a deductive method based on the categories of self-care symptom-management strategies identified by Chou *et al.* (2004:336). Following the eight category coding steps as suggested by Carley (1992, cited in Busch *et al.* 2005:3), a set of words were chosen for the level of analysis, allowing the researcher to classify different words with the same meaning. After the manual coding, the analysis yielded the various self-care symptom-management strategies as practised by women living with HIV and AIDS and experiencing HIV- and AIDS-related symptoms.

The eight category coding steps were as follows:

- decide the level of analysis
- decide how many concepts to code for
- decide whether to code for existence or frequency of a concept
- decide on how to distinguish amongst concepts
- develop rules for coding the texts
- decide what to do with additional information
- code the texts, and
- analyse the results.

During the analysis of the data, reference was made to the definitions of the eight categories of self-care strategies identified by Chou *et al.* (2004:336).

ETHICAL CONSIDERATIONS

Ethical approval was obtained from the research ethics committee of the University of KwaZulu-Natal and from the research ethics committee of the hospital to which the Sinikithemba HIV and AIDS care centre belongs. All participants gave permission to tape-record the interview, signed a consent form and were given an information document explaining the study, its advantages and possible inconvenience, as well as how any possible risks associated with participating in the study would be managed (Brink 1996:38). Anonymity and confidentiality were maintained. As a token of appreciation, the participants were given a leaflet on nutrition for people living with HIV and AIDS, compiled by the South African Sugar Association.

TRUSTWORTHINESS

Trustworthiness was achieved by ensuring credibility, dependability, transferability and confirmability. Credibility was achieved by the researcher conducting the interviews herself, allowing consistency in data collection, through member checks and debriefing, as well as prolonged engagement, as data were collected over 3 months. Providing a rich description of the details of data collection and analysis methods and setting ensured transferability. A second person reviewed the record and process, and bracketing was used to ensure dependability and confirmability.

RESULTS AND DISCUSSION

Description of participants

All participants in the study were women living with HIV and AIDS, over 18 years old and able to give their own consent, and had experienced HIV- and AIDS-related symptoms as established in the screening process using the SSC-HIVrev instrument (Holzemer *et al.* 2001:68). The respondents' ages ranged from 25 to 57 years. The period of positive HIV-status awareness ranged from less than a year to 9 years. Five participants out of the 11 were unemployed, and only two of the women reported having two breadwinners in their household, whilst four of the respondents were the only breadwinners in their household. The number of people living in the same household ranged from one to 14, and for seven of the respondents, there were at least two other people living with them, whilst only one person reported living alone.

Symptom experience

Participants reported a number of physical symptoms such as skin problems, headaches and numbness, as well as gastrointestinal and gynaecological symptoms. Psychological symptoms such as loneliness were also expressed.

In their descriptions of the symptom experience, participants highlighted the impact of symptoms on their emotional status: Some reported sadness and having uncomfortable feelings. The account of the symptom experience was accompanied by a description of the pain experience, which appeared to be severe and influenced their decisions regarding self-care symptom-management strategies for the symptoms suffered. One of the respondents explained her experience of the different symptoms as follows:

'One thing that was happening was the weakness of the leg. Because I had that. Because it was not painful, I didn't go that time, it's only when I developed the shingles then I go to the doctor.'

Self-care symptom-management strategies

The respondents' descriptions of their self-care symptom-management strategies were analysed based on the eight categories of self-care symptom-management strategies described by Chou *et al.* (2004:336). Seven categories of self-care symptom-management strategies were identified from the data (1) medication, (2) help-seeking, (3) self-comforting activities, (4) daily activities and/or thoughts, (5) complementary treatment, (6) spiritual care and (7) dietary changes.

Medication

Several participants identified taking medication as a common self-care symptom-management strategy. The medication taken was either prescribed by health care providers after consultation, purchased from a pharmacy, or a home remedy, as was evidenced by these comments:

*'I was buying the pills from the chemist' and
'The doctor gave me some painkillers and antibiotics' and
'I take only tablets from the doctor.'*

Medication was viewed by the respondents as bringing rapid relief to the symptoms experienced. The reliance on medication in the self-care management of HIV- and AIDS-related symptoms amongst these individuals is similar to what has been documented in other studies done in southern Africa (Sukati *et al.* 2005:188).

Although the use of medication was frequently reported by the respondents, some women in the study had a limited knowledge of medication. This was noted in the following narratives:

*'... because I have other medicine that I use, I don't know the name.'
'I was using a cough mixture, but still it [cough] was not going ... I forgot the name of the mixture.'*

This observation was echoed by another respondent when describing the medication she was using to manage her HIV-related symptoms:

'They [clinic staff] just give me something to apply on my skin ... it is something in the tube, and also they gave me yellow tablets for allergy.'

Such limited knowledge about the self-care symptom-management strategies employed results in people living with HIV and AIDS being totally dependent on health care providers for the management of their HIV- and AIDS-related symptoms.

Help-seeking

Help-seeking from health care providers such as doctors, clinics or hospitals was another self-care symptom-management strategy that was noted by the respondents. The women also reported that seeking help was followed by obtaining a prescription for medication to alleviate the symptoms experienced. When asked what she did for the painful swallowing that she experienced, one respondent said:

'I go to the doctor right away.'

A respondent that suffered from shingles reported:

'I go to the doctor and doctor gave me some tablets: stillpane and calamine.'

Another participant commented that when she experienced diarrhoea symptoms, she went to her nearest clinic.

Self-comforting activities

Another type of self-care symptom-management strategy expressed by the participants was self-comforting activities, which included supporting the part of the body that was painful and applying some pressure to reduce the pain (e.g. back pain). One woman stated:

'When I am sick like this I am pushing on the chair [shows how she pushes the back against the chair/wall]. And when I am sitting, I must put something; ... When I am sitting like here, I always put something between me and the wall, and drink [something] warm.'

Self-comforting also included activities such as sleeping and resting, as expressed by a participant:

'It is not for the whole time, the whole day, for the few three minutes, five minutes this thing is coming; eish, I just go to sleep.'

Washing, removing clothes, massaging the painful part of the body and drinking warm fluids, as well as soaking feet in hot water to relieve pain in the legs or toes were other self-comforting activities noted in the study.

The respondents appeared to be attempting activities that would make them feel better without the help of a professional, suggesting that the women living with HIV and AIDS do take some action to manage their symptoms.

Daily activities and/or thoughts

Daily activities and thoughts were another approach to self-care symptom management described by the women in this study. A respondent commented:

'I drive my car ... go nowhere, to town, and then I go up and down; eh; mainly during the day, or anytime when I feel like that, I go to the centre, drink some tea ... Sometimes I go with my friend if I can.'

Another explained managing her symptoms through relaxation and positive thinking, saying:

'I think it's just to relax ... that makes me feel better to tell myself that I have to accept it as it is. Try not to think negatively about it. What makes me relax is to think positively. I think it helps me with this.'

Some participants said that they did nothing for their symptoms, apart from simply enduring the pain and discomfort. Enduring

HIV- and AIDS-related symptoms has also been documented by Tsai *et al.* (2002:307). This suggests that some of the women who participated in the study lacked knowledge about the self-care symptom-management strategies that can be adopted to ease their symptoms. Some found themselves in a helpless situation, where they felt that they could not do anything to ease some of the symptoms. Such limited knowledge about the management of some of the HIV- and AIDS-related symptoms has been also suggested in Taiwan (Tsai *et al.* 2002:307), where the study participants that had endured their symptoms reported experiencing weight loss, vaginal discharge, diarrhoea and mouth sores. Not doing anything for the symptoms experienced may also be related to other barriers to self-care symptom management, such as limited financial resources as a result of unemployment and dependency on other people.

Complementary treatment

Complementary therapies were also amongst the self-care symptom-management strategies observed, and included taking traditional medication and employing harm-reduction activities, such as ceasing traditional medication when advised that it would not help. The following was reported by a respondent:

'... because my doctor said if I drink all that the treatment is not going to be alright. Because if you drink medicine for African and drink medicine for doctor, it is not right because this one will affect this one. So I stopped it. I am not drinking it anymore.'

Some participants reported other natural remedies such as gargling salt water for a sore throat, taking glucose water for diarrhoea and drinking large amounts of water for headaches. The use of complementary treatment has been reported as playing an important role in the lives of people living with HIV and AIDS in southern Africa (Sukati *et al.* 2005:190). Awareness of the type of complementary treatment that is being used is crucial in order to be able to advise the client about its effectiveness (where it has been established) and, more importantly, its safety. This is especially important in the case of herbs and other traditional medication such as folk healing, which may have a negative effect on health (Helman 1994:357).

Spiritual care

Spirituality was expressed by only one participant as a self-care symptom-management strategy and included praying and reading the Bible:

'I pray, right now I am on leave, so I pray all the time, I also read the Bible. I believe when you read the Bible you get closer to God.' She further reported that *'when you believe in God everything is possible.'*

Although spiritual care has also been documented in other studies, the limited use of spiritual care by respondents in this study is not consistent with findings such as those of Chou (2004:113), who established that women were more likely than men to use spiritual care as a self-care symptom-management strategy.

Dietary changes

Dietary changes were another aspect of self-care symptom management identified in this study. A respondent reported that when she experienced weight loss, changing her diet was her main strategy in managing that symptom:

'I try to eat health food, like fruit and vegetable, don't drink cold drinks, just drink juice that is 100%, not use oil but mainly boil the food that I cook.'

The very limited use of dietary changes was evident in this study, and shows a lack of knowledge about the use of this strategy to manage a number of symptoms. This finding appears to be different from what has been established in other studies conducted in developed countries (Tsai *et al.* 2002:307).

Performing self-care symptom-management strategies

It was observed that the women in this study used self-care strategies to alleviate more than one symptom at a time and this



was more commonly related to the use of traditional medication. When asked how an African herb had helped with her itchy skin, one participant said:

'At first I couldn't eat and was dizzy, but now I don't have it and the appetite is good.'

Another respondent replied similarly when asked about the symptom for which she takes the African potato: *'I take it because of HIV.'*

As HIV- and AIDS-related symptoms are many and present more than one at a time, similarly to observations in other studies (Bunch 2004:172), the women who participated in this study were using strategies that would target a wide range of symptoms, allowing them to manage as many symptoms as possible at the same time, thereby saving them energy and resources, especially when they had to purchase medication.

The respondents indicated that even when the strategies were not as effective as they would have expected, they continued to use them as they felt that they had nothing better available to them. This was illustrated by the following:

'As I am not taking anything to gain weight and all that, I am still gonna take it [African herb], till I can get something better that can help me more, better than this.'

For this respondent, 'something better' was ARV medication, and was the reason for her attendance at the clinic at Hope House.

It was also noted that whilst seeking help, respondents reported changing their health care providers when they felt that they were not receiving adequate help and when the symptom was not subsiding. Failure to secure assistance from one institution did not discourage women experiencing HIV- and AIDS-related symptoms; they would change health care providers to ensure that they received the help they needed, as evidenced by this statement:

'I tried to change many clinics ... Because I didn't get the help' and '... that [the first medication that was given] also never use to do anything, then I went to a private doctor.'

Barriers to self-care symptom management

Several barriers inhibiting self-care symptom management were reported by the respondents, which included limited financial resources and limited time for self-care. When the participants did not have the money available to buy what was needed for the management of their symptoms or for transport, they were forced to wait until they could afford to do so. Such situations are clear examples of how personal and environmental situations can have an effect on the self-care symptom-management strategies practised by people living with HIV and AIDS.

As some of the women were receiving disability grants, they were able to afford transport to the health care institution and to purchase the medication they felt would help ease their symptoms. The following statements attest to this:

'Before I couldn't have money to buy it. Only now I have money when I got my government grant' and 'I wait for the end of the month then I can go ... because of money and transport.'

It also appeared that the performance of self-care symptom-management strategies depended on whether the women had time for managing the symptoms. One respondent explained:

'When I am home and not working, my grandchild rubs for me.'

Another said:

'I don't have the time [to soak feet in hot water to release pain in the toes] during the day.'

This struggle to maintain a balance between the need to care for oneself and the pressure to carry out the multiple roles of women as mother and carer has been documented as being

frequent amongst women living with HIV and AIDS and those experiencing HIV- and AIDS-related symptoms (Goggin *et al.* 2001:81; Miles *et al.* 2003:351; Plach, Stevens & Heidrich 2006:59).

LIMITATIONS OF THE STUDY

The findings of the study were limited by the nature of a small-scale study; it was not possible to provide details of self-care symptom-management strategies for each symptom because of the variety of HIV- and AIDS-related symptoms experienced by women living with HIV and AIDS in the eThekweni district.

All the participants in the study were Zulu-speaking Africans and the results of this study cannot be a reflection of what is performed by other races living with HIV and AIDS in the eThekweni district. This limitation is, however, lessened by the fact that Africans are in the majority in the area and that the majority of the clients in the institution are Africans.

The individual, in-depth interviews were conducted solely in English, as the respondents and the researcher were fluent in English. This excluded data from women living with HIV and AIDS who could only communicate in other African languages and were not fluent in English.

RECOMMENDATIONS

The findings of the study indicate that women living with HIV and AIDS in the urban area of the eThekweni district of KwaZulu-Natal experience different symptoms, with predominantly physical symptoms being reported. As the women might be experiencing a number of other psychological and gynaecological symptoms, health care providers need to be aware of all the possible HIV- and AIDS-related symptoms of women living with HIV and AIDS, and to ask them specifically about those symptoms. It is also imperative that health care providers assess the risks of intimate partner violence and any other form of domestic violence, the effect of the already experienced symptoms and other challenges that might be hindering women's ability to manage their HIV- and AIDS-related symptoms, thereby lowering their quality of life. This careful questioning is important, as a limited ability to manage patients' symptoms coupled with a limited knowledge and understanding of HIV- and AIDS-related symptoms might hinder the reporting of such symptoms and delay the seeking of assistance by those experiencing HIV- and AIDS-related symptoms (Miles *et al.* 2003:351). The accurate assessment and diagnosis of experienced HIV- and AIDS-related symptoms is essential, as it allows health care agents to assist people living with HIV and AIDS to manage these symptoms.

A study is necessary to examine the activities of people living with HIV and AIDS in terms of their exercise routines to establish the benefits that could be lost as result of a possibly sedentary life. Such a study would be beneficial, as it would identify the activities that are being performed by people living with HIV and AIDS and their exercise value, in order to be able to plan further exercise for people living with HIV and AIDS. This would ensure a healthy lifestyle and assist in the identification of the kind of exercise that could be planned to manage specific symptoms, such as fatigue and depression – symptoms that have been documented to benefit from exercise (Bunch 2004:173).

CONCLUSION

The symptoms described in this study are not unexpected and are similar to what has been found in other research studies in developed countries, as well as those in southern Africa. In a quantitative study, Hudson, Kirksey and Holzemer (2004:17) found that the most frequently occurring symptoms are fatigue and muscle ache (84%), weakness (80%) and painful joints (71%). The symptoms of rashes, painful joints and headaches reported

in this study have also been described by Hudson *et al.* (2004:18). Headaches and painful joints have also been noted as prevalent in women living with HIV and AIDS by Hudson, Lee and Portillo (2003:489). Fatigue was found to be the most common symptom recorded in people living with HIV and AIDS by Hughes (2004:8S), and Shawn *et al.* (2005:16) have reported high frequencies of skin-related problems (72%) and fatigue (65%). The symptoms described by participants in this study, such as skin problems and fatigue, are similar to those found in other southern African and developed countries (Bowie *et al.* 2006:1; Goggin *et al.* 2001:85; Shawn *et al.* 2005:20). Makoae *et al.* (2005:26) also noted fatigue, headaches, painful joints and weakness – which are amongst the reported symptoms in this study.

People living with HIV and AIDS and those experiencing HIV- and AIDS-related symptoms are affected in various ways. Their quality of life often decreases; there may be an increase in depressive symptoms and a limited ability to fulfil roles, especially as mother and caregiver, as a result of the high frequency and intensity of symptoms (Holzemer 2002:50; Hudson *et al.* 2003:490; Hudson *et al.* 2004:19; Plach *et al.* 2006:62; Tsai *et al.* 2002:37). Women living with HIV and AIDS and those experiencing HIV- and AIDS-related symptoms experience interference and restriction in their daily and social lives, and this could be aggravated by skin problems such as rashes and itchy skin that could be visible to everyone (Holzemer 2002:50; Plach *et al.* 2006:59).

In this study, the respondents reported that their experience of symptoms was very often accompanied by pain, which they described along with the ways in which they managed it. The high frequency of pain experienced by people living with HIV and AIDS has been observed by other researchers (Bowie *et al.* 2006:5; Shawn *et al.* 2005:16). The pain experienced as a result of HIV and AIDS requires further investigation, since poor pain management in chronic illness is a major source of impaired quality of life. In particular, pain experienced by women living with HIV and AIDS is a major area for further research.

Several of the study participants reported physical symptoms similar to those observed by Goggin *et al.* (2001:87). Psychological and gynaecological symptoms described by the participants were infrequent, and this appears to differ from other study results (Hudson *et al.* 2003:489; Hudson *et al.* 2004:19; Makoae *et al.* 2005:31).

Nevertheless, such limited reporting of psychological and gynaecological symptoms by the study respondents may be misleading in terms of their frequency. Miles *et al.* (2003:351) noted that some women do not report many HIV- and AIDS-related symptoms as they are considered common experiences, an observation that was also documented by Helman (1994:132). This 'common experience', together with an inadequate understanding of HIV- and AIDS-related symptoms, results in the non-reporting of such symptoms. Health care providers should specifically inquire about psychological and gynaecological symptoms when interacting with people living with HIV and AIDS (Hudson *et al.* 2004:19).

Self-care symptom-management strategies practised

The practised self-care symptom-management strategies are addressed by the symptom-management dimension of the conceptual framework used in this study. The category of medication described by participants in this study has been documented in a number of studies done overseas and in southern Africa (Chou 2004:111; Holzemer 2002:50; Sukati *et al.* 2005:188). It was noted that some respondents had little knowledge about their medication; in some cases women did not know the name of the medication that they had used, especially when the medication was obtained from health care providers. Such limited knowledge is a disadvantage, as they will always have to rely on health care providers for medication even when the medication could be obtained over the counter. Help seeking as a self-care symptom-management strategy

as practised by participants in this study highlights the trust participants had in the health care providers, and also leads to overloading of health care services. In South Africa, there has been a drastic increase in the number of people using health care services as a result of the increase in HIV and AIDS prevalence. This increase puts immense pressure on health care services to accommodate all the clients at their institutions and to provide an adequate service. This situation is further being threatened by limited resources in the health services (Shawn *et al.* 2005:12; Veenstra & Oyier 2006:267).

Dietary changes as a self-care symptom-management strategy was practised by a few respondents, a finding that appears to differ from studies done in developed countries (Tsai *et al.* 2002:304). The limited knowledge about using this strategy to manage HIV- and AIDS-related symptoms must be explored further, as it is essential for people living with HIV and AIDS to maintain an adequate nutritional status.

Exercise was not described as a self-care symptom-management strategy by any of the respondents, despite an indication by previous studies that exercise may be helpful even for those with a chronic illness such as HIV and AIDS. Although the women who participated in the study were active in their daily household chores, they did not report the use of exercise as a self-care strategy for any of the symptoms that they experienced. Exercise as a self-care symptom-management strategy has been shown to be effective for various HIV- and AIDS- related symptoms in other studies (Bunch 2004:173; Kempainen *et al.* 2006:602). A lack of knowledge about the importance of exercise is a concern, and the necessity for exercise needs to be explained to people living with HIV and AIDS, especially women, as they might think exercise is unnecessary or they might view themselves as already being active. Exercise for this group of women is essential, and should be planned to help them benefit optimally from such a routine.

The women who participated in the study reported being assisted in the performance of self-care symptom-management strategies by their family members. The presence of family members and its benefit in providing support has been noted by Spirig *et al.* (2005:338). Most of the respondents had other people living with them in their household and support was available for most of them.

However, the presence of another person does not always provide support. It is well documented that most women in southern Africa living with HIV and AIDS have been infected by their male partners. Domestic violence is often encountered and many women can neither negotiate nor demand what they want or need. For that matter, they are not in a position to insist that their male partner uses a condom to protect themselves from HIV infection or re-infection. Abdool Karim's study in KwaZulu-Natal established that although 51.2% of women felt they had the right to refuse sex and 53.9% could insist on the use of a condom with partners who put them at risk of HIV infection, more than half of the women who participated in the study reported that they would have difficulty negotiating condom use with their partners, as they feared that their partners would leave them or threaten violence (Abdool Karim 2001:195).

Furthermore, it has been noted that women who were married or lived with a partner often reported more HIV- and AIDS-related symptoms than women who were single. This disparity could be a result of difficulties experienced in trying to manage their own health problems and balancing the additional demands made on them in their multiple roles as spouse, mother, homemaker and caregiver (Plach *et al.* 2006:59). Based on this high frequency of symptoms in women, health care providers should be able to assess and inquire about problems such as domestic violence and lack of support, in order to be able to manage the symptoms and ensure the well-being of women living with HIV and AIDS.

In addition, a large number of people living in the same household where there are only one or two breadwinners limits



the financial resources needed to care for them, and this increases their vulnerability (Abdool Karim 2001:195; Leenerts 1998:30). This financial stringency will result in women living with HIV and AIDS not being able to purchase the necessary medication and food for the management of their symptoms or not being able to pay transport costs to attend a health care institution (Leenerts 1998:23). The fact that most of the study participants were unemployed may also have limited their financial independence, because they had to rely on someone else to provide money for their needs. In such cases, the women living with HIV and AIDS would only be able to request any financial assistance for the self-care management of their symptoms if they had disclosed their HIV-positive status. The rate of disclosure of HIV status by women in developing countries has been documented to range from 16.7% to 86% (Medley *et al.* 2004:300). The availability of a government disability grant becomes essential to facilitate women's ability to perform some self-care symptom-management activities, such as going to a health care institution and purchasing medication, which they would not be able to do in the absence of financial support.

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