

Health care seeking behaviour of newly diagnosed HIV infected people from rural and urban communities in the North West Province of South Africa

Kruger, A. (MSoc Sc Nursing; PhD Nutrition)
North-West University, Potchefstroom Campus
Director- Africa Unit for Trans-disciplinary Health Research (AUTHeR)

Greeff, M. (MCur (Psychiatric Nursing); PhD (Psychiatric Nursing))
North-West University, Potchefstroom Campus
Researcher, Africa Unit for Trans-disciplinary Health Research (AUTHeR)
Email: Minrie.Greeff@nwu.ac.za – **Corresponding author**

Watson, M. J. (MCur Nursing; Ph D (Community Nursing; RN; RM))
North-West University, Potchefstroom Campus
School of Nursing Science

Fourie, C.M.T (B Soc Sc Honns Nursing; MSc Physiology; RN; RM).
North-West University, Potchefstroom Campus
School of Physiology, Nutrition and Consumer Sciences

Abstract

Volunteers (n=1 999) who regarded themselves as healthy enrolled in the Prospective Urban and Rural Epidemiology (PURE-SA) study in the North West Province, of South Africa (SA) after giving signed consent. All the participants, with newly identified health problems, were immediately counselled and referred to the local health clinics or hospitals with a referral letter from the principal researcher. The aim of the research was to explore the health care seeking behaviour of the newly diagnosed HIV people, after having been referred to a health care facility a year earlier, and after having received pre- and post-test counselling.

Purposive voluntary sampling was conducted. Data were collected by means of a survey, followed by an in-depth interview specifically aimed at exploring the health care seeking behaviour of HIV infected persons in the North West Province. Each researcher wrote verbatim responses of the participants as well as, demographic, descriptive and reflective field notes during and after each interview. For the quantitative data in the survey, frequency and cross tabulations were performed. The verbatim responses and field notes were analysed using the open coding technique of content analysis.

Of the 1 999 participants in the PURE-SA baseline study 16.6% (332) who considered themselves to be healthy were diagnosed with HIV. Only 27.7% (n=92) of these 332 participants had actually sought medical care after post-test counselling and referral by a health professional. Three main aspects that influenced health care behaviour of the participants were: various

forms of stigmatisation; aspects around the illness itself; poverty and other factors influencing access to health care services. Recommendations enhanced focus on stigma reduction, understanding of HIV, and factors to enhance access to health care facilities.

KEYWORDS: AIDS, health care seeking behaviour, HIV infection, AIDS, North West Province, PURE-SA study.

Introduction and Rationale for conducting the study

The Prospective Urban and Rural Epidemiology (PURE) study is a cohort study that tracks changes in lifestyles that influence the development of non-communicable diseases over a period of at least ten years (2005 - 2015), using periodic standardised data collection in urban and rural areas. This article will focus on the North West Province (NWP) of South Africa (SA) only. In the PURE-SA study, 1 999 volunteers who regarded themselves as healthy; did not report the use of any chronic medication; were not pregnant; were not inebriated; and were older than 35 years, enrolled after giving signed consent.

Although participants in the NWP of the SA study initially viewed themselves as being healthy during the baseline survey interview in 2005, some were diagnosed with illnesses like hypertension and diabetes. Screening tests for HIV identified 332 (16.6%) newly diagnosed HIV positive persons, who were immediately counselled and referred to a local health clinic or hospital (with a referral letter from the principal researcher).

The seriousness of the HIV pandemic for SA is highlighted by the UNAIDS 2008 report (UNAIDS, 2008). The report states that globally in 2007 the number of people living with HIV has risen to 33.2 million, in comparison to the 29 million in 2001. Sub-Saharan Africa remains the most affected region, with a total number of 22.5 million people living with the virus in 2007. In the report SA is indicated as the country with the largest number of HIV positive persons - an estimated 6 million. An estimated 12.7% of the people of the NWP of South Africa were living with HIV in 2006. The researchers investigated the health care seeking behaviours of newly diagnosed HIV positive persons who had been counselled and referred to health care facilities.

Background and theory of health care seeking behaviour

Ward, Mertens and Thomas (1996) refer to health seeking behaviour as the sequence of remedial actions that individuals undertake to rectify perceived ill health. Sorenson, Emmons, Hunt, Barbau, Goldman, Peterson, Kuntz, Stoddard and Berkman (2003) maintain that the various components of health behaviour will have diverse outcomes within different cultures in different countries. Cole, Holtgrave and Rios (2008) refer to factors that encourage health-relevant behaviour. They classify it into internal and external factors. Internal factors refer to knowledge about the risk factors such as attitudes, beliefs and core values' life adaptation skills' psychological disposition and physiology.

External factors refer to: social support, media, socio-cultural, political, economic and biological aspects; health care systems; environmental stressors; and societal laws and regulations.

Ahmed (2005) refers to a number of models that are used for understanding health-seeking behaviour beyond knowledge, attitudes and practice (KAP) surveys and ethnographic studies. The health-seeking behaviour models provide relevant determinants for identifying problematic areas in order to intervene with specific health system strategies (Hausmann-Muela, Riberia & Nyamongo, 2003). According to Sheeran and Abraham (1995 cited in Hausmann-Muela et al., 2003), action in the Health Belief Model (HBM) is guided by beliefs about the impact of an illness and its consequences (threat perception); health motivation (readiness to be concerned about health matters); beliefs about the consequences of health practices (behavioural evaluation); clues to action, (including internal and external factors); and conditions such as socio-demographic and psychological characteristics of the interviewed person. These factors are considered to be transformable through health education/health promotion campaigns, in contrast to structural or cultural factors like poverty, gender and religious norms. This was confirmed by Carson (2005) who mentioned that the HBM implies that a person's action to avoid disease is a function of his/her perceptions of disease susceptibility and seriousness. However, a belief to take action would not necessarily entail overcoming important social or psychological barriers. Prompt behaviour, whether it is due to an internal or an external stimulus is capable of linking perceptions to health-seeking actions (Carson, 2005).

The “four A’s” model uses different categories which group key factors for health-seeking behaviour into four A’s, namely availability (geographical distribution of health facilities and pharmaceutical products); accessibility (including transport and roads); affordability (referring to direct, indirect and opportunity costs of health services); and acceptability (relating to socio-cultural barriers) (Good, 1987 cited in Hausmann-Muela et al., 2003). The advantage of this model is the easy identification of key potential ‘barriers’ impacting on the adequacy of treatment.

In the Pathways Model, paths to utilise different health services are decided upon through recognising symptoms and the influence of extended groups of relatives and friends in illness negotiation and management (“significant others”) (Ahmed, 2005). Furthermore, individual perceptions and beliefs influence behaviour and shape a person's pathway to health care (Okello & Neema, 2007).

According to Ahmed (2005) the Healthcare Utilization Model, first proposed by Andersen in 1995, implies three categories of factors which influence health seeking behaviour namely predisposing factors (age, gender, religion, ethnicity, education occupation, social capital, knowledge and prior experience about the illness), enabling factors (household poverty, out of pocket health expenditure, perceived illness, self-reported

illness, availability of services, affordability, health insurance, and social network support) and need factors (such as perception of severity, days lost due to illness, help from outside for caring).

In Pender's Health Promotion Theory (HPT) the focus is on health promotion. The determinants of Pender's HPT are individual characteristics (gender, age, and genetics), behaviour specific cognitions and affects (perceived benefits and perceived self-efficacy affecting indications for specific behaviours) and situational/interpersonal influences (social and environmental factors that influence health (Srof & Velsor-Friedrich, 2006). Modifying factors are grouped into demographic, interpersonal and situational variables. Taking action is influenced by perceived barriers such as real or imagined inconveniences, unavailability of facilities or difficulty in reaching health-promoting services (Srof & Velsor-Friedrich, 2006).

The Theory of Reasoned Action can be explained by a study done by Manhart, Dialmy, Ryan and Mahjour (2000) on sexually transmitted diseases. They stated that once a person is infected or has symptoms, he/she is faced with the choice of seeking care. Fear that others will learn about one's illness might prevent people from seeking care until it is absolutely necessary. The role of stigma as a barrier to STD and HIV-related care is confirmed by many researchers (Holzemer, Uys, Makoae, Stewart, Phetlhu, Dlamini, Greeff, Kohi, Chirwa, Cuca & Naidoo, 2007; Varaz-Diaz, Serrano-Garcia & Toro-Alfonso, 2005; Fortenberry, McFarlane, Bleakley, Bull, Fishbein, Grimley, Malotte and Stoner, 2002).

A study done in Cambodia (Khun & Manderson, 2007) refers to behavioural factors and specifically mentions economic, structural and institutional factors that contribute to delays in treatment seeking. These include access to health facilities, quality of care and time costs, as well as costs of transportation and the ability to pay for prescribed medication. Poverty is a key factor influencing whether or not people can meet the direct and indirect costs of treatment. Poorer households use health services less frequently, delay seeking medical advice, and fail to adhere to treatment recommendations. This trend is the sharpest in very poor communities and countries, where cash resources are limited (Ahmed, Petzold, Kabir & Tomson, 2006).

RESEARCH METHODOLOGY

Research design

This study (done in 2006) was nested within the SA leg of the larger randomised longitudinal international PURE cohort study in which annual follow-up home visits are scheduled between August and November. A survey and an exploratory and descriptive

qualitative research design (Cresswell, 1994) were followed. The phenomenon of health care seeking behaviour of newly diagnosed HIV people was explored.

Objectives

The aims of the study were to explore whether people newly diagnosed with HIV and having received pre- and post-test counselling did follow through on the referrals made to a health care facilities a year previously, and what their health care seeking behaviours were during the past year.

Research method

Population

Rural and urban communities which represented four different strata of urbanisation in the NWP of SA and where the history of participants predicted relative stability regarding migration were identified for the longitudinal PURE-SA study. The urban communities in the NWP were chosen in and around Potchefstroom. Community A was selected as an established urban community from the established part of the township next to Potchefstroom and community B as an informal community from the informal settlements that surround community A. Rural community C is situated 450 km west of Potchefstroom on the highway to Botswana and the deep rural community D is 35 km northeast of community C and only accessible by a gravel road. Both rural communities are still under tribal law and have the same chief.

Sampling

Purposive voluntarily sampling (Burns & Grove, 2001) was conducted. The inclusion criteria stated that participants should all be people from the urban and rural areas enrolled in the baseline 2005 survey of the PURE-SA study who were newly diagnosed with HIV and who had been referred to a health care facility of their choice. In total, 332 participants (115 men and 217 women) from both urban and rural areas were included.

Ethical considerations

The PURE study protocol complies with the Helsinki Declaration as revised in 2000 and was approved for the study by the Ethics Committee of the North-West University (number: 04M10). Permission was also obtained from the Provincial Department of Health of the NWP, the local government authorities of each town as well as the tribal chief in the rural communities where the study was conducted. Participants were provided with background information about the study and the purpose thereof. They were

also informed that participation was voluntary and that they could withdraw at any time. They were assured of confidentiality. Before enrolment in the study, as well as with every follow-up action, all participants gave informed and written consent. Sixteen fieldworkers (8 living in the urban and 8 living in the rural communities) were trained about ethical issues such as mutual respect and the importance of confidentiality during home visits.

Throughout the study, care was taken to maintain the anonymity of all information. Informed consent for a home visits was obtained from each participant during the individual feedback sessions, in which laboratory results and/or post-test counselling were given. Before the home visits, participants were reminded by the fieldworkers of the researchers' intentions to conduct interviews. During the home visits, informed consent was obtained from the participants to conduct the interview.

Data collection

Setting

In both the urban and rural communities, the participants were interviewed in the privacy of their own homes, without disturbances.

Survey and Interviews

Data were collected by means of a short survey list, followed by an in depth interview specifically aimed at exploring whether participants followed up on the referrals to health care facilities after being diagnosed with HIV. The survey list focused on information about age, sex, number of clinic or hospital visits, whether a person was using ART and also reported on participants who had died within the 12 months since the baseline survey had been done during 2005. The survey was enriched from the clinic cards, which were in the possession of the participants and were voluntarily shown to the researchers. Information on treatment and visits to clinics were gained from these cards. If the newly diagnosed HIV infected person accessed a health care facility for health care, blood was drawn and CD4 cell counts done in the pathology laboratory at the local hospitals. The hospital managers made these results available to the researchers after each participant signed informed consent to enable the researchers to access these hospital files.

The researchers were all nurses who were skilled in the technique of interviewing and were responsible for conducting the in-depth interview. The in-depth interviews were initiated by the following single open-ended question:

“Last year, after we tested your blood, you were referred to the clinic. Tell me what you did about this after we referred you?”

The question was evaluated in a pilot study done during the first week of August 2006 with 10 participants and it took on average half an hour to conduct the interview. The fieldworkers acted as translators when necessary. Each researcher wrote the participants' verbatim responses as well as demographic, descriptive and reflective field notes during and after each interview.

Analysis

Statistical analyses

To describe differences in health care seeking behaviour descriptive statistics were performed on the quantitative data in the survey using the Statistical Package for the Social Sciences (SPSS version 15).

Analysis of the interviews

The verbatim responses and field notes compiled by each researcher from the interviews were analysed using the open coding technique of content analysis of Tesch (in Cresswell, 1994). Categories and sub-categories were identified and themes developed.

Trustworthiness

The model of Lincoln and Guba (in Krefting, 1991) was used to ensure trustworthiness. The criteria of credibility, transferability, dependability and conformability were ensured as indicated in table 1.

Table 1: Trustworthiness of the research

Criteria	Strategy	Application
Truth value	Credibility: triangulation	Interviews were conducted by experienced researchers; field notes were taken and the theory reviewed; a trial run was done of the interview schedule.
	Peer examination	An evaluation of the research proposal by peer reviewers; interview schedule evaluated by experts.
	Prolonged engagement	Researchers were known in the community and a relationship of trust existed; an extended time was spent with the participants.
	Reflexive analysis	Three researchers were involved; field notes were written to ensure that observations and experiences were captured.
Consistency	Dependability and transferability: code-recode	Data were analysed by all the researchers; consensus discussions were held to reach consensus about themes and sub-themes.
	Dependability audit	The verbatim capturing of the interviews and field notes made auditing possible.
	Dense description of research methods	Detailed description of the methodology makes the study repeatable.
Neutrality	Confirmability: confirmability audit	Field notes can be made available for auditing.

RESEARCH RESULTS

The community profile regarding available medical and HIV services is shown in table 2. In the urban as well as the two rural communities clinics were fairly easy to access, as none of these were more than five kilometres from the participants' households. In all the communities, ART was available at the provincial hospitals. The hospital in the urban areas (communities A + B) is easy to reach (not more than 8 km), whereas the hospital in the rural area is 15 km by tar road from community C and more or less 45 km on a mainly gravel road from community D. Participants in all communities used taxis for transport. The taxi fare was determined by the distance travelled.

Table 2: Community profile regarding medical and HIV services

	Number of clinics within community	Distance to hospital (ART)
Formal urban (community A)	1	2-4 km
Informal Urban (community B)	2	4- 8 km
Rural (community C)	1	15 km
Deep rural (community D)	1	45 km

Table 3 reveals the data from the survey relating to HIV status and treatment. Of the 1,999 participants in the NWP of the PURE-SA baseline study, 16.6% (n=332) of the people who thought they were healthy, were diagnosed with HIV. The mean age (44 years) of those participants infected with HIV did not differ between the urban and rural communities. More participants lived in the rural communities (17.7%; n=176) than in the urban communities (15.6%; n=156). In both urban and rural communities more women than men were newly identified to be HIV infected (217 females compared to 115 males).

Only 8.7% (n=29) in the urban communities sought care at a health care centre, compared to the 18.9% (n=63) in the rural communities. There was also a difference between the two rural communities: 44.6% (n=41) of the newly identified HIV infected participants visited a health care facility from the rural community C, compared to only 26.2% (n=22) in rural community D. In the urban communities more men than women visited the health care facilities, whereas in the rural community there were no gender differences between the percentages of those who sought care at health care facilities.

Of participants who sought care at a health care facility, the CD4 cell counts of 6.9% (n=23) were below 200 cells/mm³ and they were given ART. Of these 23 participants, 9 came from urban communities and 14 from rural communities. In the urban community more women (2.1%; n=7) than men (0.60%; n=2) were receiving ART, while in the rural community 2.4% (n=8) of the men and 1.8% (n=6) of the women received ART.

Of the HIV infected participants 5.4% (n=18) died within a year after they had enrolled in the study. The number of deceased in the urban and rural communities did not differ. Four men and five women died in the urban community within one year, while three men and six women died in the rural community.

Table 3: Community profile regarding HIV status and treatment

Community	Participants Total	Participants mean age	Participants HIV+	HIV+ Mean age	HIV+ Visited hospital or clinic	HIV+ on ART	Participant deaths within 12 months
A	(n)	Years (SD)	n (%)	Years (SD)	n (%)	n (%)	n (%)
Men	208	50 (10.3)	32 (15.3%)	44 (7.9)	6 (18.8%)	1 (3.1%)	4 (1.9%)
Women	292	52 (11.5)	60 (20.5%)	45 (8.4)	11 (18.3%)	6 (10.0%)	1 (0.3%)
B							
Men	188	50 (10.3)	23 (12.3%)	46 (9.5)	5 (21.7%)	1 (4.3%)	0 (0%)
Women	315	49 (10)	41 (13.0%)	43 (6.6)	7 (17.0%)	1 (2.3%)	4 (1.2%)
C							
Men	188	48 (9.5)	36 (19.1%)	44 (7.1)	16 (44.4%)	5 (13.8%)	3 (1.5%)
Women	317	48 (9.6)	56 (17.6%)	43 (7.2)	25 (44.6%)	3 (5.3%)	5 (1.5%)
D							
Men	156	51 (11)	24 (15.3%)	45 (9.4)	7 (29.1%)	3 (12.5%)	0 (0%)
Women	335	48 (9.8)	60 (20.5%)	42 (7.3)	15 (28.3%)	3 (5.6%)	1 (0.3%)

Themes derived from interview data

The analysis of the verbatim responses and field notes identified a number of themes that could explain participants' the lack of health care seeking behaviours. The reasons from urban and rural areas were similar.

Stigmatisation

The participants were careful to reveal their status as they were fearful of being stigmatised by the community. They identified stigma in the form of fear of being rejected by their families, their partners or other community members: *“If people know you will be pushed aside by the community”*. The participants also feared facing the reality of their HIV diagnosis during the follow-up visit to the health care centre. Some participants expressed their fears follows: *“Going to hospital means you are HIV infected”*. During the pre-test counselling group sessions with all participants, the majority of participants

expressed their concerns and fears of being stigmatised: *“People do not know or understand this illness”*. When permission was requested during post-test counselling to do follow-up home visits a year later, one female participant quickly answered: *“You should not come to my house ... please do not visit me ... they will know if strangers visit me ... no I don't want them to know”*

During the baseline data gathering process few participants responded to the question whether they knew anyone in their area of residence who had HIV or AIDS. This might have been an indication of a sense of respect and non-disclosure towards other HIV positive persons.

Fear of being sexually unacceptable

Some women in the urban communities said that if it should become known that they attended the HIV/AIDS clinic, men would regard them as being sexually unacceptable. *“They do not look at me anymore”*. They thus feared losing their sexual acceptability and becoming isolated.

Lack of support when ill

When the participants were extremely ill, they often experienced a lack of support from in their communities. Most participants felt that support from civic organisations and from their neighbours and other community members was non-existent. One participant remarked:

“... the people do not care ... the neighbours ... some say bad things like why should their children die and mine is still alive ... I do not understand ... we do not trust each other any more”.

Absence of symptoms led to denial

Because participants did not feel sick did not believe the results of the HIV tests or felt that they did not need treatment. During a group discussion arranged to motivate the participants to visit their health care centres for follow-up confirmation, one of the participants confided the following: *“... I know that it could be HIV, but we don't want to hear it, you see they tested me for TB and my husband died of cancer, he was very weak and in bed ...”*

Denial was also observed during post-test counselling when more than one participant who had lost a husband, wife, partner, family member and/or friend would say that they did not know the cause of these family members' deaths.

Belief that HIV does not kill

Some participants reported that they did not believe that HIV would kill them. The reasons for people dying, according to them, were not due to HIV but to other illnesses “*I have TB ... HIV will not kill me*”.

HIV is a death sentence

Some participants denied their HIV positive diagnosis others were devastated by this news believing that they had received death sentences. Therefore, they did not believe that seeking health care would change their destinies. One participant stated: “*I know I am going to die ... why will I go?*”

Four male participants refused to go to the clinic for confirmation of their HIV positive diagnoses. One of the participants said: “*All my family members and friends that go to the clinic for the test and hear that they have the virus, die*”.

Too ill to access health care services

Many participants said it was simply too much effort to attend the health care facility when they felt so ill. It was just too much trouble to walk the distance to the health care facility or to wait for long periods at the health care facilities. “*I am so weak ... I cannot walk so far or wait so long ...*”

Poverty reduces access to health care services

In the rural community where poverty is extreme, the distance to health care centres becomes a severe limitation to access health care services and it affects health care seeking behaviours: “*If you do not have money to eat you cannot use money for a taxi*”. Although most participants indicated that they lived closer than five kilometres from the health care facility, some were old or ill: “*I just don't have the courage to walk*”. In the rural areas some participants had donkey-carts for transport, but this could be very exhausting and time consuming. One male participant responded “*... I will rather stay at home and rest ...*”

Beliefs about western medicine

Some participants did not believe in western medicine and used their own, culturally acceptable treatments for HIV/AIDS.

“*I will use our own stuff ... I can trust it*”. Most participants, however, used both the lo-

cal health care services, seen as “westernised medicine”, and their traditional medicine or cultural practices.

Quality of care rendered by health care workers

Some participants (especially in community D) complained about the behaviour of the health workers at the health care facilities. They said health workers shouted at them and did not show them any respect: “*They shout and tell you to wait for long... They will shout at me and say I am a silly man ... for me that is not nice ... what do they mean ... they swear at me ... they look down on me*”.

For these reasons some participants did not want to go to the health care facilities for help and did not have the money to go to private doctors.

DISCUSSION

The survey’s results

As many as 16.6% (n=332) of the 1999 participants older than 35 years, who thought they were healthy, had been diagnosed with HIV infection. This could mean that prophylactic testing and/or that health education and prevention strategies were unsuccessful. HIV could thus spread because people did not know their status. Only 27.7% (n=92) of the 332 participants sought medical care after extensive post-test counselling and referrals by professional persons. More participants from the rural communities (18.9%; n=63) sought health care in their areas, compared to the 8.7% (n=29) in the urban communities. This is contrary to results of other studies (Hausmann-Muela et al., 2003; Manhart et al., 2000). However, there is a marked difference in the percentage of participants from the two rural communities seeking health care. Of the participants in community C (rural), 44.6% (n=41) sought care at the hospital, compared to 26.2% (n=22) in community D (deep rural). In community C the clinics and HIV support groups were reportedly active and more supportive than those in the deep rural community D. Also, many participants from the deep rural community D complained about health workers’ behaviours. The effect of poor quality care has been confirmed by Holzemer et al. (2007). Community D, was the poorest; and poor communities do not prioritise access to health care (Ahmed et al., 2006). The infection rate was slightly higher in the rural area (17.7%; n=176) than in the urban area (15.6%; n=156). More women were infected and on ART, but more men accessed the health care facilities.

Of the 92 participants who had visited health care centres, 23 (25.0%) started using ART because their CD4 cell counts were below 200 cells/mm³, indicating that they had AIDS

and were ill. Out of 333 participants, 5.4% (n=18) saw themselves as healthy but died within the first year of the PURE-SA study.

The interviews

Three main aspects influencing health care behaviours of the participants emerged from the interviews: various forms of stigmatisation (fear of stigma, fear of not being sexually acceptable, and lack of support); aspects around the illness itself (absence of symptoms led to denial, HIV does not kill, HIV is a death sentence); and factors influencing access to health care services (too ill to get there, poverty preventing access to transport, cultural beliefs and poor quality of care and respect).

The first three themes might indicate that people feared stigmatisation and did not access available health care services. These findings confirm the work done by Greeff et al. (2008). Although this study did not specifically address stigmatisation per se, it tried to understand why only 92 of the 322 people sought health care despite counselling sessions at baseline to motivate the participants to visit health care facilities. The study on HIV stigma conducted in five African countries (Naidoo, Uys, Greeff, Holzemer, Makoe, Dlamini, Phetlhu, Chirwa & Kohi, 2007) indicate that more incidents of stigmatisation and discrimination were reported in urban than in rural groups. Both Naidoo et al. (2007) and Skinner and Mfecane (2004) mention that stigmatisation separates people from others and creates a feeling of superiority for those who are not affected, as well as a feeling of shame towards those who are affected. This could explain why fewer urban (8.7%; n=29) participants sought health care than those in the rural areas (18.9%; n=63). This is according to the findings of Naidoo et al. (2007) who reported that urban groups described more incidents of stigmatisation and discrimination. However, back in 1993, Rost, Smith and Taylor reported that rural residents labelled people more harshly than their urban counterparts being associated with poorer utilisation of health care services. If support is available, stigmatisation can be addressed and access to health care services enhanced.

Greeff et al. (2008) found that although both men and women experienced stigma, Malawian and SA women consistently reported more incidents of stigma than men. The other two countries – Tanzania and Swaziland – reported more incidents among males, with Lesotho reporting lower figures than the other four countries. This study also found more infected women similar to other HIV studies (Greeff et al., 2008). The only gender differences in health care seeking behaviours were observed in the informal urban housing areas (Community B), where more men (21.7%; n=5) than women (17%; n=7) sought help. However, just visiting a health care facility could be associated with being HIV infected. Most people (72.2%; n=240) in this study made the choice not to expose themselves to this risk. That might be an indication of the level of stigmatisation in the

communities because according to Holzemer *et al.* (2007), the more severe the stigma in a specific community, the less likely people will be to access health care services.

It was difficult to unravel the role that stigmatisation versus ignorance or denial played in the health care seeking behaviours of participants. Yet, specific themes supported the idea of ignorance and denial: an absence of symptoms led to denial; HIV does not kill; HIV is a death sentence. During home visits, some participants became agitated when they told the researchers that HIV could not cause death. This may reflect a failure of HIV health education or prevention programmes, because ignorance could be due to a lack of knowledge of even wrong messages being conveyed to these communities. The possible failure of health education programmes was also reflected in the basic HIV knowledge of participants as encountered during the pre- and post-test counselling sessions. However, during the home visits, a few participants from community C told the researchers that they had not yet attended a health facility because they were still “strong” and asymptomatic. The participants stated that if they could maintain good nutrition, they could postpone the use of ART. By contrast, some participants lost hope after their HIV positive diagnosis, despite the counsellors’ efforts. Greeff *et al.* (2008) found that many people alluded to suicide after hearing their initial HIV positive diagnoses. The participants who had lost hope did not seek medical help because they believed they would die in any event.

The factors influencing access to health care services were identified as being too ill to get there, being too poor to afford the means of travel to get there, cultural beliefs, poor quality of care and a lack of respect. Poverty, contributed to the lack of health care seeking behaviours, especially in community D (deep rural). The main source of income for these participants was government grants. Travelling was extremely expensive for these participants. Although the clinic was five kilometers or less from their households, ill patients might be unable to reach it on foot. The hospital could only be reached by transport. The lack of funds could explain the different percentages of participants who sought health care in the rural communities, as supported by Khun & Manderson (2007).

Cultural belief systems also played a major role in failure to access health care services. Some participants believed that the medication at the health care centres which kill them and they preferred their “own stuff” from their “own doctor”. Pinkoane, Greeff and Williams (2007) report that 80% of the black population of SA still prefer to visit traditional healers. The researchers were also challenged with the question “Did you ever see HIV stated as a reason for death on a medical certificate?” Some participants did not understand that in SA, HIV/AIDS was not mentioned on death certificates issued to families of the deceased, to protect them from stigmatisation.

Participants reported that the quality of health care was poor. They did not want to go to

the clinic or hospital because they might spent the whole day waiting to be helped and they felt too ill to endure that. The waiting time could be due to staff shortages and/or to patient overload. Some reported being screamed at by health care workers, illustrating a lack of respect for these patients. This was also found by Greeff et al. (2008).

Eighteen (5.4%) HIV infected participants died within one year of the study, although they had regarded themselves to be healthy during the baseline survey. There were no differences between the urban and rural communities with regard to the deaths of the participants, as nine participants were from the urban communities and nine from the rural communities. Only one participant died while receiving ART. This participant was from community C and sought care at the hospital shortly after being diagnosed as being HIV infected. This participant's CD4 cell count was only 135 cells/m³ when ART was started. The reason for death on the death certificate was stated as "unknown".

CONCLUSIONS

The aim of this paper was to report on the health care seeking behaviour of 322 newly diagnosed HIV infected participants who had been intensively counselled and referred for treatment. Only 92 participants (27%) visited free health care facilities. Stigmatisation prevented participants from seeking health care. A supportive social environment, encouraged health care seeking behaviours, as seen in community C, where the highest percentage of newly HIV infected participants sought health care. Socio-economic influences and demographic characteristics impacted on health care seeking behaviours in community D. Ignorance about HIV/AIDS was widespread and cultural beliefs prevented some people from seeking health care.

RECOMMENDATIONS

The following policy and practice recommendations are suggested to enable better health care seeking practices in the NWP:

Stigma reduction programmes should be implemented and more resources allocated to empower HIV support groups. Effective and well-informed groups can be of great support not only to communities, but also to health workers. In this regard the inclusion of traditional healers as part of support groups should be considered. HIV infected persons should be treated with more discretion at health care facilities and hospitals, to minimise stigmatisation.

Understanding of HIV/AIDS must be enhanced. Uncertainties, denial and misconceptions persist. The cause of death (in the case of HIV infected patients) should be made known to family members (provided health care policies allow this), so that these family

members can make informed decisions about accessing voluntary HIV counselling and testing services.

More should be done to take the service to the patient in under-resourced areas or deep rural areas where poverty is intense. Traditional healers and cultural practices should be acknowledged and co-operation established between the various health care providers.

REFERENCES

- Ahmed, S.M. 2005. *Exploring health-seeking behaviour of disadvantaged populations in rural Bangladesh*. Stockholm: Division of International Health (IHCAR), Department of Public Health Sciences, Karolinska Institute. Available at URL: (Accessed on November 2008).
- Ahmed, S.M., Petzold, M., Kabir, Z.N. & Tomson, G. 2006. Targeted intervention for the ultra poor in rural Bangladesh: does it make any difference in their health-seeking behaviour? *Social Science & Medicine*, 63:2899-2911.
- Burns, N. & Grove, S.K. 2001. *The practice of nursing research: conduct, critique and utilization*. 3rd Edition Philadelphia: W.B. Saunders.
- Carson, A.J. 2005. "What brings you here today?" The role of self-assessment in help seeking for the age-related hearing loss. *Journal of Aging Studies*, 19:185-200.
- Cole, G.E., Holtgrave, D.R. & Rios, N.M. 2008. Internal and external factors that encourages or discourages health-relevant behaviour. Available from URL: http://www.cdc.gov/DHDSPP/cdcynergy_training/Content/activeinformation/resources/Health_Behavior_F
- Cresswell, J.W. 1994. *Research design: qualitative and quantitative approaches*. Thousand Oaks: Sage.
- Dorrington, R., Johnson, L., Bradshaw, D., Daniel, T.J. 2006. The demographic impact of HIV/AIDS in South Africa. Available from URL: www.commerce.uct.ac.za/care or www.mrc.ac.za/bod or www.assa.org.za (Accessed November 2008).
- Fortenberry, J.D., McFarlane, M., Bleakley, A., Bull, S., Fishbein, M., Grimley, D.M., Malotte, C.K. & Stoner, B.P. 2002. Relationships of stigma and shame to gonorrhoea and HIV screening. *American Journal of Public Health*, 92(3):378-381.
- Greeff, M., Uys, L.R., Holzemer, W.L., Makoae, L.N., Dlamini, P.S., Kohi, T.W., Chirwa, M.L., Naidoo, J. & Phetlhu, D.R. 2008. Experiences of HIV/AIDS stigma of persons living with HIV/AIDS and nurses from five African Countries. *Africa Journal of Nursing and Midwifery*, 10(1):78-108.
- Hausmann-Muela, S., Riberia, J.M. & Nyamongo, I. 2003. *Health-seeking behaviour and the health system response*. London: London School of Hygiene and Tropical Medicine (DCPP Working Paper No. 14).
- Holzemer, W.L., Uys, L.R., Makoae, L., Stewart, A., Phetlhu, D.R., Dlamini, P., Greeff, M., Kohi, T.W., Chirwa, M., Cuca, Y. & Naidoo, J. 2007. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing*, 58(6):541-551.
- Krefting, C.L. 1991. Rigor in qualitative research: the assessment of trustworthiness. *American Journal of Occupational Therapy*, 45(3):214-222.
- Kuhn, S. & Manderson, L. 2007. Health seeking and access to care for children with suspected dengue in Cambodia: An ethnographic study. *BMC Public Health*, 7. Available from URL: (Accessed November 2008).
- Manhart, L.E., Dialmy, A., Ryan, C.A. & Mahjour, J. 2000. Sexually transmitted diseases in Morocco: gender influences on prevention and health care seeking behaviour. *Social Science & Medicine*, 50:1369-1383.

- Naidoo, J.R., Uys, L.R., Greeff, M., Holzemer, W.L., Makoae, L., Dlamini, P., Phetlhu, R.D., Chirwa, M. & Kohi, T. 2007. Urban and rural differences in HIV/AIDS stigma in five African countries. *African Journal of AIDS Research*, 6(1):17-23.
- Okello, E.S. & Neema, S. 2007. Explanatory models and help-seeking behavior: pathways to psychiatric care among patients admitted for depression in Mulago Hospital, Kampala, Uganda. *Qualitative Health Research*, 17(1):14-25.
- Pinkoane, M.G., Greeff, M. & Williams, M.J.S. 2005. The patient relationship and therapeutic techniques of the South Sotho traditional healer. *Curatationis*, 28(4):20-30.
- Rost, K., Smith, G.R. & Taylor, J.L. 1993. Rural-urban differences in stigma and the use of care for depressive disorders. *Journal of Rural Health*, 9(1):57-62.
- Skinner, D. & Mfcecane, S. 2004. Stigma, discrimination and the implications for people living with HIV/AIDS in South Africa. *Journal of Social Aspects of HIV/AIDS*, 1(3):157-164.
- Sorenson, G., Emmons, K., Hunt, M.K., Barbau, E., Goldman, R., Peterson, K., Kuntz, K., Stoddard, A. & Berkman, L. 2003. Model for incorporating social context in health behaviour interventions: applications for cancer prevention for working-class, multi-ethnic populations. *Preventive Medicine*, 37(3):188-197.
- Srof, B.J. & Velsor-Friedrich, B. 2006. Health promotion in adolescents: a review of Pender's Health Promotion Model. *Nursing Science Quarterly*, 19(4):366-373.
- UNAIDS. 2008. Report on the global AIDS epidemic.
- Varaz-Diaz, N., Serrano-Garcia, I. & Toro-Alfonso, J. 2005. AIDS-related stigma and social interaction: Puerto Ricans living with HIV/AIDS. *Qualitative Health Research*, 15(2):169-87.
- Ward, H., Mertens, T.E. & Thomas, C. 1996. Health-seeking behaviour and the control of sexually transmitted disease. *Health Policy and Planning*, 12:19-28.

Acknowledgements

The authors would like to thank all supporting staff and the participants of the PURE-SA study, and in particular:

PURE-SA: The PURE-SA research team in the NWP, fieldworkers and office staff in the Africa Unit for Trans-disciplinary Health Research (AUTHeR), Faculty of Health Sciences, North-West University, Potchefstroom, South Africa.

PURE International: Dr S Yusuf and the PURE project office staff at the Population Health Research Institute (PHRI), Hamilton Health Sciences and McMaster University. ON, Canada.

Funders: SANPAD (South Africa - Netherlands Research Programme on Alternatives in Development), South African National Research Foundation (NRF GUN numbers 2069139 and FA2006040700010), North-West University, Potchefstroom, South Africa and PHRI, Ontario, Canada.