Needs Experienced by Persons with Late Stage AIDS

by **Fred C. Rabbetts and Steve D. Edwards**

Abstract

The paper examines needs experienced during the late stage of AIDS with reference to a phenomenological explication of unstructured interviews with persons with acute symptoms of the disease. A distinct pattern of health care needs emerged, characterized by a relative emphasis on the psychosocial as distinct from biomedical or economical aspects of the disease and emotion focused coping strategies. Results are compared with those of other studies and implications for palliative care are discussed.

INTRODUCTION

The health needs of persons with late stage AIDS are particularly urgent in KwaZulu-Natal, a province on the east coast of South Africa, where the prevalence of infection is the highest in the country and the infected population has entered the syndromal phase of the disease. Recent estimates are that one in three people have HIV in Zululand, an area north of the Tugela river in KwaZulu-Natal (Mason & Wood 1994; Ndukwana 2001; Nyawose 2001).

In that persons with late stage AIDS had increasingly requested terminal care in the Richards Bay area of Zululand, the need for the establishment of a comprehensive terminal care facility, or AIDS Care Centre, in the area became apparent. This study was launched as a needs analysis to provide informed recommendations regarding services and facilities to be provided at such an AIDS Care Centre.

The general aim of this paper was to explore needs experienced during the late stage of AIDS. As survival periods from the time of an HIV positive diagnosis and awareness of the psychosocial co-factors in disease progression increase, there is a growing concern for the quality of life that has been extended and a need for research to clarify the variables that determine emotional strength and coping of the person with AIDS (Friedland, Renwick & McColl, 1996; Schlebush & Cassidy, 1995; Sher, 1990; Sliep, 1994).

The specific aim was to collate the explicated needs of persons with late stage AIDS in the Richards Bay area in KwaZulu-Natal, South Africa, with services and facilities available to them through state and welfare structures. Recommendations drawn from this collation informed decisions regarding facilities and treatment to address unmet needs at an AIDS Care Centre in the area.

Additionally, this research was aimed at allaying the high levels of prejudice among both the public and those in the helping profession towards persons with AIDS, evident in practice and in recent research, by providing an unbiased description of their needs (Van der Berg, 1992; Eagle & Bedford, 1992).

A better understanding of the needs of persons with AIDS has preventative implications as well. Research has shown that the stress induced by having HIV/AIDS prompts attempts to reduce it by engaging in unhealthy behaviour such as unsafe sex and

intravenous substance abuse (Temoshok & Braum, 1990; Thompson et al., 1966).

METHOD
Subjects

Direct experience of late stage AIDS, the ability to articulate this experience, a willingness to be open to the interviewer and naivete with regard to theories about the researched phenomenon were essential criteria for the selection of respondents. Interviewees who qualified for treatment in an AIDS Care Centre on the basis of symptoms (including Carpossi Sarcoma, pneumonia, AIDS related venereal diseases etc.) and/or low CD 4 counts were considered to have direct experience of late stage AIDS. All twelve subjects selected were fluent in English (the language interviews were conducted in) and only one interview had to be rejected because pervasive denial obstructed the ability to articulate the experience of late stage AIDS openly to the interviewer, as required in qualitative phenomenological studies of this nature (Giorgi, 1985; Stones, 1986).

Additionally the sample was limited to persons currently or previously employed by companies participating in the research. Since these companies offered medical and financial support to persons with HIV/AIDS, this introduced the possibility of bias. Immediate financial problems and unemployment did not emerge as such immediate concerns as in related research with samples of unemployed persons with HIV/AIDS (e.g. Mason & Wood, 1994).

Procedure

A phenomenological research procedure, conforming to the format outlined by Kruger (1986), Spiegelberg (1982), Stones (1986) and Van Vuuren (1989), was applied in the steps outlined below:

- The identification of the phenomenon.
- The selection of subjects.
- The first person description (interview and protocol).
- Repeated reading the description or protocol or protocol in order to get a sense of the whole.
- Breaking each protocol down into Natural Meaning Units (NMUs), which refer to the smallest naturally occurring units of experience which appeared in each protocol.
- Reduction and linguistic translation of the Natural Meaning Units into themes.
- Formulating the situated structure for each subject.

- Formulating the general structure (synthesis) for all individual protocols.
- Discussion: relating the explicated needs of persons with late stage AIDS to current theory.
- The research report: an overview, evaluation and recommendations.

According to Polkinghorne (1989, p. 46) the general format for phenomenological research may be summarized as follows:

- Gather a number of naive descriptions of the phenomenon under investigation (in this case late stage AIDS) through unstructured interviews with persons who are experiencing it.
- This meant asking a sample of persons with late stage AIDS the essential research question ("What are your needs as a person with late stage AIDS?"). This is an unfocussed, highly projective question - "projective" in the sense that the question means whatever the respondent wishes to make it mean, which is precisely that aspect of their experience of the phenomenon that the research aims to explicate.
- Naturally this research question evoked a flood of information. From the perspective of a phenomenological study and reflective generative practice, it was important to elicit interviewees' conceptualization of key issues and agenda for the research and subsequent intervention. Therefore the interviewee set the agenda for the interview. In practice this approach had the additional benefit of ensuring community relevant, valid research and intervention.

Reflective-generative practice refers to a relationship between research and the application thereof characterized by dialogue within the community as the basis for generating community-relevant knowledge to guide relevant community intervention (Dokecki, 1992). The principles of Paulo Freire with their emphasis on empowerment, relevance, authentic dialogue and problem posing are incorporated in reflective generative practice (Freire, 1970).

All the interviews were conducted at clinics at the participating companies. Home interviews were avoided since home environments would not provide long enough periods (around sixty minutes) without interruptions or distractions and were perceived by interviewees as threatening due to fears of branches of confidentiality. A standard introductory format was used prior to opening each of the interviews with the

same projective, general question (`Can you tell me more about your needs as a person with AIDS?'), followed by the use of non-directive interviewing techniques. Permission was secured to audiotape interviews and the resulting protocols were transcribed into individual and collective profiles (Kruger, 1988).

Due to lack of time it was not possible to secure reflected summaries and consensual validation through giving feedback to respondents of specific situated structures or themes and obtaining their validity judgement. The contract research was conducted to inform services and facilities provided at an AIDS Care Centre (ACC) and had to be completed in less than one and a half months after which the budget for the ACC would cease to be available.

To compensate for any possible lack of consensual validation the interviewer summarized and reflected during the original audio taped interviews at points of natural closure all the themes generated thus far and confirmed from the respondent that this was a valid reflection of his concerns and needs.

Results

The interviewees in the present study articulated a distinct pattern of primarily psychosocial health care needs (mainly for improved coping and social support) with the experience of late stage AIDS.

The following is a description of the generative themes as they emerged from an explication of the protocols, cited in the order of frequency with which they appeared on the basis of the numbers of Natural Meaning Units referring to them.

Distraction

An overwhelming need to remain distracted from an awareness of their illness, as a means of coping, emerged as the most frequently cited need during the experience of late stage AIDS. This seemed to be more related to lack of social support and fears of rejection than guilt or associated attributions of themselves as unworthy of care. Fears of rejection and expected oppositional attitudes were experienced as coercing interviewees to maintain a facade of health and normality in the face of emotional alienation from families and members of their communities.

Therefore stereotypes and stigmatization emerged, as in other related research (Lindegger & Wood, 1995), as major variables complicating the experience of living and dying with AIDS.

Caring relationships

The second most frequently cited need was for a nurturing stable relationship with caregivers characterized by empathy and compassion in an inpatient format. This caring relationship was construed as establishing a sense of belonging and a shared sense of being human that were both affirming and facilitated transcendence of awareness of their illness.

Awareness of the physical implications of their illness

Awareness of the physical implications of the disease emerged as the third most frequently cited experience during late stage AIDS. These (such as awareness of weight loss and related infections) were experienced as constant, inescapable, painfully tangible reminders that interfered with one's ability to remain distracted from awareness of the disease. Additionally the physical signs and symptoms of AIDS were detected by family and friends and resulted in fears of rejection and denial of the disease.

Family and community

The experience of family and community emerged as the fourth most cited aspect of late stage AIDS. Family and friends were experienced as emotionally demanding and lacking empathy and understanding. Interviewees withdrew from them owing to fear of rejection and expectations of having to cope with their sense of loss and distress about their illness.

Confidentiality

Fears of breaches of confidentiality emerged as the fifth most cited aspect of the experience of late stage AIDS. There was a need for the AIDS Care Centre to be on company grounds (and not in the communities, where prejudice and rejection were experienced as most intimidating) and have access control.

Attitude

Attitude towards having AIDS was the sixth most frequently cited aspect of having late stage AIDS expressed in interviews. Interviewees emphasized the terrifying sense of helplessness experienced when they thought about having AIDS. As a remedy for this they suggested that one should accept responsibility for having the disease and avoid constant preoccupation with this awareness.

Material support

As breadwinners (all the interviewees were male and employed by companies participating in the research), respondents cited a need for alternative provision of material support for their direct and extended families as the seventh most frequently cited concern in interviews.

Exercise

A need for exercise, as a means of promoting a sense of well being during relatively symptom free periods emerged as the eighth most cited need in interviews. This was followed by need for the AIDS Care Centre to be in a peaceful environment and for a sense of hope that there would be a possibility of cure (in the face of media messages emphasizing the terminal nature of the disease).

DISCUSSION

Varying needs of persons with AIDS in different settings

The interviewees in the present study articulated a distinct pattern of needs with the experience of late stage AIDS that does not correspond with that suggested by research by Mason and Wood (1994) or Marazzi et al. (1994). Whereas this research indicates that material needs (accommodation and concerns with issues such as childcare and medical facilities) are the most serious problems encountered in the later stages of AIDS, the interviewees in the present study expressed a predominant desire for emotional support and improved coping.

While this reflects the varying characteristics of the different samples used (with the research of Mason and Wood, 1994, for example, using a sample of unemployed Zulu adults and the present study employing a sample of employed male Zulu adults), it is also a testimony to the varying needs, stages and contexts of persons with AIDS in different settings that make generalization difficult.

In this regard, Doka (1993, p. 32) states that the course of HIV/AIDS is different for each individual and is influenced by the actual experience, in terms of preceding psychosocial experiences and pre-existing psychological problems. Berk, Baigis-Smith and Nanda (1995) emphasize that the precipitous changes in physical and emotional health status throughout the trajectory of the disease and the concomitant psychosocial and physiological problems present a challenging complexity of the health care needs of persons with HIV/AIDS that refute generalizations. Accordingly Flaskerud (1992) recommend that care and treatment for persons with HIV/AIDS should vary from one setting to another and across diverse clinical manifestations of the disease. Therefore the following discussion and collation with related research of the generative themes as they emerged in the present study should be considered firstly as an expression of the experience of late stage AIDS in this specific target community.

Distraction, coping and related issues
Distraction as emotion focused coping

The overwhelming need for distraction from an awareness of having AIDS seems, as mentioned, more related to perceived community intolerance and rejection than issues of self blame and/or guilt as forms of personal attribution (Anderson et al., 1991; Grummon et al., 1994; Lindegger & Wood, 1995).

Rejection and stigmatization were ascribed to others' prejudice and lack of insight rather than any personal sense of guilt or culpability (as attributional styles associated in research with reduced active or positive coping ability). Lack of social support, fears of rejection and oppositional attitudes were experienced as coercing the interviewees to maintain a facade of health and normality in the face of emotional alienation from their families and communities (Lindegger & Wood, 1995).

Additionally thinking about having AIDS resulted in morbid introspection. The accompanying distress, awareness of its immune suppressing role (many interviewees correlated it with a relapse of acute symptoms) and a sense of futility due to the inescapableness of death prompted efforts at transcendence from awareness of their illness.

This prominence of emotion focused coping strategies is to be expected in the late stage of AIDS, as the acute phase of a terminal illness. Emotion focused coping refers to efforts at managing the distressful emotions that accompany problems whereas problem focused coping refers to efforts directed at managing the problems that are causing the distress themselves. Research with chronic illness in community samples has shown that people use more problem focused coping strategies (including 'confrontative coping' and 'playful problem solving') in encounters they appraised as changeable and employed emotion focused coping strategies (such as 'distancing', 'escape-avoidance', 'accepting responsibility' and 'positive reappraisal') in encounters in which they felt their options for affecting the outcome were limited (Grummon et al., 1994).

Caring relationships

In this regard interviewees experienced interactions with staff at company clinics as facilitating distraction in awareness of their illness through humour and a sense of empathy. The latter was particularly important since it provided them with a sense of belonging and alleviated their profound sense of being outcasts from their families and communities. They expressed a need for similar helping relationships at the AIDS Care Centre. The primary need attached to emotionally sustaining relationships (as the second most cited theme) corresponds with

related research regarding changes in the needs of persons with HIV/AIDS for social support with the progression of the disease. Accordingly those in the earlier stages of HIV favoured informational support whereas persons with ARC (AIDS Related Complex) and AIDS preferred emotional support (Friedland et al., 1996). This trend echoes the above mentioned increasing emphasis on emotion focused rather then problem focused coping strategies with the progression of the disease.

Yet, in their efforts to stress the importance of distraction, the interviewees cited mostly incidents portraying inadequate emotion focused coping resulting in morbid obsessions, feelings of depression, acute distress and even suppressed immune response. While this corresponds with findings in related research (Friedland et al., 1996; Mulder, 1992), it indicates the need for psychological intervention aimed at facilitating emotion focused coping through acceptance of their illness.

Stereotypes and stigmatization
Relationships beyond those with staff at company clinics were not experienced as helpful. In common with findings by O'Rawe, Amenta and Tehan (1991) the persons with AIDS in this study experienced notable social isolation, extending to their families of origin.

Stereotypes and stigmatization emerged as major variables complicating the experience of living and dying with AIDS. Attitudes of family members and the general public were experienced as ambivalent at best and outright oppositional at worst.

Families and friends were not experienced as sources of emotional or social support, but rather as potential burdens in terms of their emotional reactions to their illness. Thus interviewees generally refrained from disclosing their illness to meaningful others for fear of their reactions and of burdening them with their problems. Buuren (1992) had similar findings. Accordingly persons with AIDS often erect barriers between themselves and potential caregivers due to concerns about loss of independence, fears about burdening loved ones, or out of the need to avoid the high emotional costs associated with maintaining the relationship. Conversely it has also been shown that caregivers withdrew from helping relationships in the later stages of AIDS due to physical or emotional exhaustion and over identification with the patient (Smith & Rapkin, 1995).

Seeley et al., (1993) found in a study in Uganda that the extended family did not in fact provide adequate social support for persons with AIDS, despite the common assumption that it provides social and economic support for its members in times of need in African contexts. Various reasons were given for this by carriers, including lack of money, food, medications and the carer's other responsibilities and commitments. Research by Mason and Wood (1994) with unemployed Zulu speaking adults with AIDS revealed similar findings, with the family cited most frequently as the main source of support (mainly material or financial), but this help being experienced as inadequate and seeming to rest on the condition that their HIV status remains hidden. In the present study the interviewees, as present or past employees of companies participating in the research, were generally the only breadwinners in extensive extended families and expressed some concern for the material well-being of their dependents after their death.

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About the Authors

Dr Edwards has had a long-term commitment to phenomenological methodology and has published extensively in the area of community-based psychology, indigenous psychology, healing and mental health. He actively contributes to clinical health practice in South Africa.

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