In patients with symptomatic HIV disease, spirituality emerged from stigmatisation and having an incurable disease

Hall BA. *Patterns of spirituality in persons with advanced HIV disease*. *Res Nurs Health* 1998 Apr;21:143–53.

Question

How do people with advanced (symptomatic) HIV disease structure spiritual meaning?

Design

Interpretive interactionism.

Setting

USA.

Patients

5 men and 5 women aged 32–38 years who had symptomatic HIV disease (CD4 count <300) and identified themselves as having had spiritual or religious experiences that helped them to cope with their disease. 6 were European-American, 2 were Mexican-American, 1 was African-American, and 1 was Native-American.

Methods

During 2–3 hours of interviews, patients were asked to describe spiritual experiences and beliefs that helped them deal with HIV and to explain how these experiences changed their lives or their views of the meaning of their illness. Interviews were audiotaped and transcribed verbatim. Data were collapsed into themes over 3 iterations. Findings were corroborated by patients at initial and follow up interviews. Study patients and the staff and clients of 2 organisations that served people who were HIV positive reviewed the initial study report.

Main findings

3 major themes were constructed to show how personal meaning emerged from a rejecting social context and the knowledge that one had limited time to live. The first theme, *purpose in life emerges from stigmatisation*, depicted patients' multiple rejections from family, friends, and religious institutions. After they became HIV positive, patients separated from the larger society and a meaning emerged that was largely free from the values of estab-

lished belief systems. Patients attributed their new spirituality to the opportunities that HIV provided to their lives (eg, to make a difference in the fight for acceptance). Obstacles and constraints informed meaning. Patients reconnected with family.

The second theme, *opportunities for meaning arise from a disease without a cure*, described how patients incorporated their illness and symptoms into their understanding of their spiritual being. When first diagnosed, most patients felt depressed and engaged in self destructive behaviour. Eventually, some encouraging or challenging event disrupted self destruction. Patients gained confidence in recovery, took more control, and selected treatments that felt right to them. The fear patients experienced when they realised that their time was limited was ameliorated by an awareness that there was still a lot of life before death and that all people eventually die. They became more hopeful, accepted health information, and actively sought social support.

The third theme, *after suffering, spirituality frames the life*, showed the development of a spiritual understanding of life. Patients cleared their lives of stressful and meaningless aspects (eg, hated jobs) and embraced those that strengthened their faith and defined personal meaning. Meaning in life involved finding ways to help others. Patients developed a personal philosophy to deal with unanswerable questions about death, and performed daily spiritual rituals. They began to experience a sense of empowerment to deal with whatever came up, and a desire to make changes in their lives.

Conclusions

In patients with symptomatic HIV disease, spiritual meaning emerged from the rejecting and stigmatising social context of HIV and from the experience of dealing with an incurable disease. After the experience of suffering, spirituality framed their lives.

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Commentary

The study by Hall can help nurses to better understand patients' spiritual experiences of AIDS related illness. The results resonate with personal testimonies of people diagnosed as HIV positive and with the epidemiology of survival patterns.

The study described how participants overcame societal and professional expectations of death after a positive diagnosis of HIV. Experiences of fear and despair as well as a growing awareness of the limitations of scientific orthodoxy enabled spiritual empowerment. The key finding focused on how individuals uncovered and used strategies to enhance

their spirituality. The study thus provides a broader perspective of a person's spirituality and can assist nurses to place spiritual care more firmly within their care planning activities. Although participants identified spirituality by referring to God or a higher power, much spiritual expression was not related to church or religion. Personal faith often took the form of a unique spiritual meaning.

The study described the complexity of individual responses to a positive diagnosis of HIV. For example, the findings may encourage nurses to look beyond some of the contemporary simplistic discourses on compliance,¹ which are often found in

research on HIV medications. The findings also show how the reality of patient decision making is always situated within a complex spiritual-social milieu.

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1 Royal Pharmaceutical Society of Great Britain Working Party. *From compliance to concordance. Achieving shared goals in medicine taking*. London: Royal Pharmaceutical Society of Great Britain, 1997.