

Informal caregivers described 3 strategies to search for meaning in caring for a person with HIV

Carlisle C. *The search for meaning in HIV and AIDS: the carers' experience.* *Qual Health Res* 2000 Nov;10:750–65.

QUESTION: What are informal caregivers' emotional experiences in caring for people with HIV?

Design

Grounded theory.

Setting

North west England, UK.

Participants

20 caregivers (age range 20–69 y; 50% men) who were homosexual men, or lesbian or heterosexual women in a range of relationships with a person with HIV (partners, friends, or parents).

Methods

Data were recorded from 43 indepth interviews with caregivers and participant observation at HIV and AIDS volunteer organisations. Each caregiver participated in ≥ 2 interviews (1–2 h). Interviews were tape recorded and transcribed verbatim. A fieldwork diary was used to record experiences and observations. Theoretical sampling and data collection continued until theoretical saturation for each category was achieved. Data were analysed using a constant comparative method.

Main findings

The main theme described in this report was *the search for meaning* or the ways caregivers balanced the costs and rewards of caregiving. The 3 strategies used by caregivers to find meaning were *[placing] the virus in perspective*, *getting involved in the HIV field*, and *[recognising] the "gift" of AIDS*. In *[placing] the virus in perspective*, caregivers accepted the presence of the virus while acknowledging their emotional pain. They focused on "living with" rather than "dying of" HIV. The stress of physical caregiving needs and their own emotional pain in coping with terminal stage AIDS led many caregivers to use detachment, disengagement, and illusion strategies for short periods. Caregivers also found meaning in their experiences by *getting involved in the broader field of HIV work* either in formal (eg, volunteer) or informal (eg, giving personal accounts of their experiences) ways. This involvement was motivated by a reaction to society's views on HIV and a desire to help others. Each caregiver spoke of the positive contribution of HIV/AIDS to their personal lives, *[recognising] the "gift" of AIDS*. The caregiving experience prompted a conscious reappraisal of feelings, the ways feelings were expressed, and personal value systems. Caregivers felt they had experienced personal growth. The "gift" of AIDS for men was related to improved relationships, whereas women experienced the "gift" at an individual level after the person with HIV had died (eg, becoming more assertive in getting emotional needs met, gaining independence and freedom).

Conclusions

The search for meaning was a powerful way in which caregivers balanced the emotional costs and rewards of caring for people with HIV. 3 strategies used to find meaning were *[placing] the virus in perspective*, *getting involved in the HIV field*, and *[recognising] the "gift" of AIDS*.

COMMENTARY

The study by Carlisle focuses on the lived experiences of those caring for a person who is HIV positive. It contributes to the growing acknowledgment of the value of listening to caregivers,¹ the relevance of the family to the care of those with life threatening conditions,² and the ability of people to become experts and gain satisfaction from undertaking the caregiving role.³

The research design and methodology is well suited to the area of investigation, and there is evidence that interviews were done in a sensitive and ethical way. This article addresses *the search for meaning*, one of the subcategories of findings that emerged from a larger study. It would have been helpful for the reader to be able to place this subcategory in context by having access to a list of the other categories.

The findings of this research are particularly relevant to all nurses. The caregivers, given a voice here, were able to show their commitment to caring. It is therefore important that they are explicitly included in the assessment and planning of care. It is also clear that these caregivers developed a high level of expertise which, if used, could enhance their own self esteem and provide help to other individuals and organisations. Finally, these caregivers exhibited considerable strength under stress. When considering empowerment issues, nurses might reflect on how, in some cases, they themselves could be empowered by these informal caregivers. Most of the caregivers in this study were able to access health and social care. This area of research requires further investigation, preferably with a group of more isolated caregivers, who may not experience the positive aspects of caregiving in the same way.

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- 1 Brechin A, Walmsley J, Katz J, et al, editors. *Care matters: concepts, practice and research in health and social care*. London: Sage Publications, 1998.
- 2 Whyte D, editor. *Explorations in family nursing*. London: Routledge, 1997.
- 3 Nolan M, Grant G, Keady J. *Understanding family care: a multi-dimensional model of caring and coping*. Buckingham: Open University Press, 1996.

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