

Caring for the chronically and terminally ill

Daglid, W., Sliep, Y., Akintola, O. & Duckert, F. 2011. Response-ability in the era of AIDS: building social capital in community care and support. Bloemfontein: Sun Media. 299 p. Price: R200,00. ISBN: 978-1-920383-14-5.

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This book is appropriately divided into five sections, namely the introduction, broader community and system responses, home-based care and volunteering, other perspectives on responsibility to HIV and Aids, and conclusions and a vision. The text is based on the three constructs of social bonding, social bridging, and linking at individual, family, community and external/governmental levels. The authors also focused on creating dialogue between practitioners,

academics, researchers, trainers and facilitators in the field of HIV and Aids.

The cooperation of all relevant organisations in the community is addressed here, as well as the link and cooperation between community and governmental health care. The issue of care for the caregivers is also discussed. Caring for chronically and terminally-ill persons can be stressful and is associated with negative physical and emotional outcomes.

Volunteerism as another important issue is addressed. Volunteering provides crucial learning opportunities and leadership development for those who volunteer. The challenges placed on volunteers in the age of AIDS include issues such as secrecy, isolation, and their own emotional and financial problems. It was found that volunteers need a salary and other support such as transportation and material to perform their job well. They also need training, supervision and support from government. A chapter is devoted to those non-volunteer caregivers and the unacknowledged dimensions of care work.

For care workers to deal with people whom they care for deeply and respond to the additional tasks, creates additional stress. These informal care providers are vulnerable to burnout, infection and illness. Often they do not have access to basic amenities, do not receive much support themselves, and may be discriminated against due to the stigma attached to the epidemic. Often carers are themselves HIV infected and in need of care. They suffer economic costs and reduced food security, and furthermore face exacerbated levels of poverty as their care work detracts them from other productive activities. Generally they are restricted from opportunities for personal development, as they often have to be removed from school or employment. Social grants and ARVs, inadequate primary input from government, shame, misconceptions, mistrust, as well as emotional and instrumental support are also covered.

The section on the challenges experienced by researchers and field-workers made for interesting reading. Issues under discussion in this section are: not being properly introduced to the community, the presence of dangerous animals during fieldwork, poor infrastructure, lack of suitable locations for interviews, and illiteracy. The text also covered well-being, optimism, hope and resilience in HIV and Aids-infected persons. The issues surrounding home-based care were discussed under the headings of, for example, the Aids care economy and community empowerment and resources. The issues surrounding community care and support are discussed together with

the matter of groups and networks at bonding, bridging and linking levels. In the last chapter conclusions are provided and some excellent recommendations are made.

This publication focuses on a couple of important issues regarding the HIV and Aids pandemic such as community members' perceptions of and participation in the care and support activities regarding HIV and Aids, volunteer caregivers, caregivers without a choice (non-volunteer caregivers), untapped resources for HIV and Aids care as well as support and building social capital in community care and support. This publication is written for the indigenous African situation and should fill a space in the wealth of publications on this topic. Although most of the authors have a background in psychology, this publication should play an important part in establishing the field of HIV and Aids care in a multiprofessional context.

The integration of theory with practice can also be seen as a highlight of this publication. Each and every project reported on in this book has a linkage between the theory and practice of the specific topic. It should also be pointed out that various research methodologies were employed. In most cases mixed-methodology research was done using a variety of methods such as participatory action research, ethnography, focus groups and in-depth interviewing. Although many authors were involved in writing the various chapters, a holistic, multimethod approach was evident throughout the text.