

Title: A systematic review of the experiences of caregivers in providing home-based care to persons with HIV/AIDS in Africa.

Reviewers:

P McInerney
P Brysiewicz

Review Panel:

P McInerney
P Brysiewicz

Commencement Date: 1 August 2004

Completion Date: 1 June 2005

Background:

Sub-Saharan Africa is the region worst affected by HIV/AIDS. In November 2003, Sibiya wrote that 29.4 million people were living with HIV/AIDS.¹ He goes on to say that “approximately 3.5 million new infections occurred there in 2002, while the epidemic claimed the lives of an estimated 2.4 million Africans in the past year.”¹ Sibiya goes on to state that in four southern African countries, the national HIV prevalence rate has exceeded 30% - these are Botswana (38.8%), Lesotho (31%), Swaziland (33.4%) and Zimbabwe (33.7%).¹ Recent figures for two centres in KwaZulu-Natal, South Africa revealed that of a total of 912 women tested for HIV, 341 were HIV positive (37.4%).² One hundred and fifty-eight of these women were aged between 18 and 25 years.²

The mounting morbidity and mortality of HIV/AIDS has placed an increasing burden on the already overburdened health services. In 2001, Nsutebu, Walley, Mataka and Simon wrote that “... around 65% of adult medical in-patients are HIV-seropositive in urban hospitals of countries such as Zambia.”³ As a result, the burden of care has moved to the community and the family. Communities have responded to this need by developing home care services to support the families in need. The provision of care to terminally ill persons places a heavy burden on the family in terms of labour, finance and psycho-social stress.⁴ Dealing with a person with HIV/AIDS can place a great strain on the caregivers. The primary caregiver within the family has both physical and emotional demands made on his/her own health, e.g risk of infection, stigma, fear and omnipresence of death.⁵ Furthermore, caregivers are usually women and in some cases girl children.⁵

Currently there are reports of the experiences of caregivers in home-based care, but there is no evidence that these experiences have been synthesized in order to promote the best practices in home-based care. It is anticipated that information generated may be used in the education of health professionals through whom caregivers in the community can be better equipped in knowledge and resources, so that practice is improved.

Review question:

- What are the experiences of caregivers in providing home-based care to HIV/AIDS clients in Africa?

Objectives:

The objectives of this review are to:

1. describe the experiences of caregivers of HIV/AIDS victims in home-based settings in Africa
2. describe the problems / difficulties experienced by caregivers in these settings
3. identify positive aspects related to the provision of care, such as the provision of resources

Criteria for considering studies for this review:Type of studies:

Phenomenological or other studies that generate experiential descriptions. Narrative, opinion and discussion papers will also be considered. Papers describing the experiences of caring for both adults and children in home-based settings will be included.

Types of participants:**Inclusion criteria:**

- Family members who are the primary caregiver of the HIV/AIDS person (adult and children) in Africa
- Volunteers from the community who provide home-based care to HIV/AIDS clients in Africa

Types of interventions/activity/phenomena:

Delivery of home-based care

Types of outcome measures/types of data:

The types of data will include experiential accounts of caregivers.

Search strategy for identification of studies:

The search strategy will be designed to access both published and unpublished materials and will comprise of the following stages:

1. a limited search of CINAHL and Medline to identify relevant keywords contained in the title, abstract and subject descriptors
2. terms identified in this way and the synonyms used by respective databases will be used in an extensive search of the literature
3. reference lists and bibliographies of the articles chosen from those identified in stage 2 above will be searched

4. unpublished abstracts will be searched through NEXUS

Articles published in the last 10 years in English (1994 – 2004) and indexed in the following databases will be searched: CINAHL, Medline, *SABINET*, EMBASE, AIDSline. African journals (Curationis, SA Health/Gesondheid and Africa Journal of Nursing and Midwifery) and journals not indexed in databases will be manually searched. The timeframe, 1994 – 2004, has been chosen because home-based care was only introduced in a number of African countries in the late 1980's and early 1990's.⁶

Initial search:

This will use the following terms:

- Home-based care
- Domiciliary care
- Community based care
- Experiences of caregivers
- HIV/AIDS
- Community health nursing
- Home health agencies
- Home health care

Methods of review:

Critical appraisal:

- The retrieved articles will be assessed by two reviewers for their suitability for inclusion as evidence is evaluated. Assessment of the quality of the study methodology will be undertaken using the QARI Critical Appraisal Tool (See Appendix I) and the NOTARI Critical Appraisal Tool (See Appendix II).

Disagreements between the two reviewers will be resolved by discussions held with a third reviewer.

Data extraction:

Data will be extracted making use of the data extraction tool of the qualitative assessment and review instrument (See Appendix III) and data extraction tool of the NOTARI data extraction instrument (See Appendix IV).

Data synthesis:

Data will be synthesised making use of the data synthesis tool of the qualitative assessment and review instrument.

Potential conflict of interest

No potential conflict of interest is anticipated

References

- 1 Sibiya M. AIDS statistics. www.dfi.org.za/issues/aids/aids_statistics.htm 2003, (accessed 21 May 2004).
- 2 Ramjee G. (2004) Medical Research Council: Microbiocide Research. Presentation to the Medical Research Ethics Committee University of KwaZulu-Natal, 4 May 2004.
- 3 Nsutebu EF, Walley JD, Mataka E, Simon CF. Scaling-up HIV/AIDS home-based care: lessons from Zambia. *Health Policy and Planning* 2001;16: 240-247.
- 4 Kerkhoven R, Jackson H. Developing AIDS care in Zimbabwe: A case for residential community centres? *AIDS Care* 1995;7: 663-674.
- 5 Phaladze NA. The Plight of Family Caregivers in Home Based_Care in Botswana. 1st SADC Conference on Community Home Based Care. www.hdnet.org/Gaberone 2001, (accessed 16 April 2004).
- 6 Uys LR. The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *J Clin Nurs* 2002; 11: 99-108. In: Sims R, Moss VA. *Palliative Care for People with AIDS*, 2nd ed. London: Edward Arnold, 1995.

Qualitative Assessment and Review Instrument (QARI)

Interpretive and Critical Research Findings Critical Appraisal Instrument

REF No. _____

Criteria	Yes	No	Unclear
1) There is congruity between the stated philosophical perspective and the research methodology.			
2) There is congruity between the research methodology and the research question or objectives.			
3) There is congruity between the research methodology and the methods used to collect data.			
4) There is congruity between the research methodology and the representation and analysis of data.			
5) There is congruity between the research methodology and the interpretation of results.			
6) There is a statement locating the researcher culturally or theoretically.			
7) The influence of the researcher on the research, and vice-versa, is addressed.			
8) Participants, and their voices, are adequately represented.			
9) The research is ethical according to current criteria or, for recent studies, there is evidence of ethical approval by an appropriate body.			
10) Conclusions drawn in the research report do appear to flow from the analysis, or interpretation, of the data.			
TOTAL			

Reviewers Comments:

From *Qualitative Assessment and Review Instrument (QARI)*, The Joanna Briggs Institute, Adelaide, 2003.
Used with the permission of the Joanna Briggs Institute.

QARI

Qualitative Assessment and Review Instrument

Data Extraction Tool

Methodology	
Method	
Intervention	
Setting	
Geographical	
Cultural	
Participants	
Data Analysis	
Authors Conclusion	
Reviewers comments	

Appendix III

NOTARI TEXTUAL CRITICAL APPRAISAL INSTRUMENT

Criteria	Yes	No	Unclear
1) Is the source of the opinion clearly identified?			
2) Does the source of the opinion have standing in the field of expertise?			
3) Are the interests of patients the central focus of the opinion?			
4) Is the opinion's basis in logic/experience clearly argued?			
5) Is there reference to the extant literature/evidence and any incongruency with it logically defended?			
6) Is the opinion supported by peers?			
TOTAL			

Reviewers Comments:

NOTARI Data Extraction Instrument

Author: _____

Record Number: _____

Journal: _____

Year: _____

Reviewer: _____

Method
Methodology
Data Analysis

Setting & Context

Geographical Context

Cultural Context

Participants:
<i>Number:</i>
<i>Description:</i>

Interventions

Conclusions	Narrative Description	Qual of Evid. Rating 1,2,3

Authors conclusion
Reviewers conclusion

