Annotated bibliography on care in the context of HIV and AIDS

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by

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In the context of a pandemic in which over 33 million people are living with HIV and AIDS, the need to provide care for people as they become ill through opportunistic infections and eventually – even in the context of accessible anti-retroviral treatment (ART) – die, is becoming increasingly relevant. However, the countries in which the epidemic is greatest, in terms of absolute numbers of, and percentages of, people living with HIV and AIDS, have the least capacity to provide meaningful care through a state system of public hospitals. As UNAIDS has pointed out, this means that around 90 percent of care for people living with HIV and AIDS is provided in the home. This crisis in care has emerged through a confluence of factors, ranging from Structural Adjustment Programmes imposed on states in Africa, which imposed user-fees and limited social spending, forcing people to exit the public health system, to the high rate of health worker migration to developed countries. This has resulted from the high burden of care demanded by people living with HIV and AIDS, the demand this places on already stretched hospital systems, and the fact that HIV and AIDS remains a highly stigmatised illness, with people choosing to die at home, rather than in public health facilities. In this context, care within the home and community is increasingly recognized as a central issue in understanding and responding to the impacts of HIV and AIDS.

The shift from hospital to home care for people living with HIV and AIDS has become formalised under the term ‘task shifting’. Task shifting is included in policy and programmes of international, regional and national organisations, and refers to the process by which work is reorganized within formal and informal health care settings, and tasks are moved ‘downwards’ from doctors to nurses, and from nurses to lay workers and volunteers. For caregiving in homes and communities, the formal recognition of task shifting creates a space and opportunity for structures of support to emerge. Yet at the same time, this shifting of work has been described as the abrogation of state responsibility, especially when such actions are implemented without adequate support. In the late 1970s and early 1980s, a similar process emerged with the rise of community health workers, as a way to

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improve primary health care. Yet, as Gill Walt\textsuperscript{6} has noted in her review of three community health worker programmes, while these programmes helped to increase the reach of health services, they did little to improve the lives of the poor women who ran these programmes. Reviewing the experiences of the 1970s and 1980s Lehmann and Sanders\textsuperscript{7} point to how such programmes work only with extensive support from organisations and communities.

The provision of care for people living with HIV and AIDS is one aspect of Universal Access, which countries signed up to as part of the UN Special General Assembly.\textsuperscript{8} Yet, compared to treatment and prevention, the need for universal access to adequate care has received little attention. This annotated bibliography provides a summary of the academic body of work on care in hopes of encouraging further research.

### Key issues

In reviewing the literature a number of salient themes and issues emerged. The themes that become apparent are: i) the huge burden that care places on individuals, families and communities, ii) the gender, class and age nature of this caregiving, iii) the relatively limited research exploring the social context in which care is undertaken, iv) the limited academic research done on interventions to support caregivers, and v) the limited research done on the changing nature of care in the context of anti-retroviral treatment.

1. **Burden of care on caregivers, families and communities**

   Since early on in the epidemic there has been extensive research on the huge burden that HIV and AIDS places on individuals, families and communities; from negative psychological, economic and social impacts.\textsuperscript{9} The vast majority of work on caregiving explores the burden of care on individuals doing the caring; less however, has explored the wider affect of caregiving on families and communities, although increasingly this is emerging, particularly through an emphasis on food security\textsuperscript{10} and vulnerability.\textsuperscript{11}

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\textsuperscript{6}Walt, G. (1990) *Community Health Workers in National Programmes: Just another pair of hands?* Milton Keynes: OUP


\textsuperscript{8}UNGASS (2001) *Declaration of Commitment on HIV/AIDS.* New York: UN


2. **The gender, class and age nature of caregiving**

Women are the main caregivers for people living with HIV and AIDS, both in the formal health sector and in the informal care economy. While a body of work is starting to identify how men’s role in caring is overlooked, women still are the main group providing care. Alongside the ‘gender’ dimension of caregiving is the class nature of caregiving. Poorer women are more likely to provide care than richer women, since care can be bought by those with enough money. Furthermore, the social, economic and psychological impact of HIV and AIDS, including caregiving, is greater for those who are poorer than those who are better off.

There is also a substantial amount of research emerging on the age of caregivers. Given that the majority of people living with and dying of HIV and AIDS are between 15 and 49, two different issues are starting to emerge. First, young people are increasingly being called on to undertake caregiving roles. Second, the elderly are increasingly taking on the role of primary caregivers.

3. **Limited research on the social context of caregiving**

Most research on caregiving has focused on the impacts of caregiving on the individual, or on the family unit. While this is an important area of concern, less research has focused on the wider social context of caregiving; such as the institutional structures (NGO, government and so forth), the funding structures, and the legal structures, which makes caregiving possible and help explain the impact of caregiving on caregivers.

4. **Limited research on interventions to support caregiving**

The rise of home-based care has been paralleled by the rise of interventions to support such caregiving. Interventions have been small and large, driven by states, international NGOs, local government, national and local NGOs and all seek to mitigate the burden of care or improve the care that can be provided through such responses. Yet despite the proliferation of such interventions, little research — available in the academic realm — has been conducted on what works, and what does not work, and why. Furthermore, such research needs to not just focus on the impact of caregiving on the quality and availability of care, but needs to move beyond this to explore what positive and negative impacts care work has on those involved, if home-based care is not to repeat the mistakes of the past and simply be another pair of hands.

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5. The changing nature of caregiving in the context of antiretroviral therapy

The importance of care giving around HIV and AIDS first emerged in a context where a diagnosis of HIV and AIDS was effectively a death sentence. Anti-retroviral therapy (ART) was either not available or too expensive for the majority of people in southern and eastern Africa to access. States refused to implement ART programmes for a variety of reasons. Now, as numerous studies emerge, highlighting that not only does ART work in resource poor settings, but adherence is as high, if not higher than in the global north,\(^\text{15}\) demand for ART roll-out increases and the nature of care giving changes. While research has been focused on the extent to which caregivers can support ART adherence,\(^\text{16}\) broader issues emerge as to the role home-based caregivers can play in supporting people on ART, and the new care needs of people on ART. The changing context of caregiving in an era of ART is an area that needs further research and consideration.


Methodology and layout

Through an extensive search of online databases (PubMed, Web of Science, African Journals Online, and International Bibliography of Social Science (IBSS)), alongside a manual review of cited literature within identified academic articles, this annotated bibliography presents summaries of key articles on caregiving. Naturally there were choices of inclusion and exclusion, resulting in omissions of what others may consider ‘key’ articles. This review also excluded ‘grey literature’ from civil society and government. The aim was to provide summaries of a range of articles that reflected the diversity of academic research on caregiving, in the Southern African Development Community (SADC), or more widely where it could directly pertain to SADC.

The annotated bibliography is presented according to

1. Impact on caregivers;
2. Who does the caregiving?
3. Social context of care;
4. Interventions to support caregivers; and
5. Care and ART.

Summaries of key articles are presented under each theme by alphabetical order. A short summary of key issues and ideas is also presented under each heading.
Impact on caregivers

There is a large body of literature on the social and economic impacts of HIV and AIDS on caregivers. The literature on economic impacts generally focuses on the household level, drawing on surveys and ethnographic research. One of the earliest studies, by Baylies, argues that due to structural adjustment policies, and other changes in social spending during the 1990s, care became privatized in the household, placing the economic burden largely on women. Within this context, a number of studies review the costs of care, and the difficulty caregivers face in balancing care demands and maintaining paid employment.

Within impact studies, discourses on coping emerge as a critical theme. Rugalema argues that the language of coping, commonly used in rural livelihood studies, obscures the struggle that many households face as they attempt to provide care in a context of multiple long term negative impacts. The thin line between coping and struggling is further taken up by research on the social and psychological impacts of the epidemic. Many of these articles focus on the individual, exploring how stigma and psychological strains impact caregiver well being. Throughout the research, emphasis is on how increasing burdens of care are impacting the already vulnerable and overburdened.


This article explores the explicit assumption in many policy documents that home-based care is more cost effective than hospital care in southern Africa. It reviews available literature on home-based care to argue that costings of home-based care are too narrow and that a wider assessment of the true cost would need to include a focus on: i) who home-based caregivers are, ii) the services home-based caregivers provide, iii) the motivation of home-based caregivers, and iv) the implications of home-based care for caregivers. The article also points out the limited costings of home-based care in the region. It concludes that there is no evidence to support the assertion that home-based care is cheaper than hospital care and suggests that further research is needed into this issue.


This paper examines how volunteer caregivers near Durban, South Africa cope with the numerous challenges of providing home-based care to people living with HIV and AIDS. The ethnographic study, including in-depth interviews and observations, followed 20 volunteer caregivers participating in a non-governmental organization program.
It found that volunteers faced a number of challenges: 1) They experienced denial, stigmatization and fear from the families of potential patients; 2) They struggled when faced with the physical reality of the very ill, and their own limitations as caregivers; 3) Maintaining confidentiality was difficult due to pressure from family members of patients; 4) Patients often became rude, depressed and angry, which added an additional burden on to the caregivers; 5) Caregivers felt pressured to help mitigate the extreme poverty of the patients; 6) Friends, family members and others questioned the role of volunteers, suggesting caregivers should only work for pay and/or undervaluing volunteer work.

The study describes how volunteers developed ongoing coping strategies to deal with these challenges and stressors, but that these coping strategies were often focused on the needs of the patients not of the caregivers. It therefore suggests there is a need for further training for volunteers, and greater support for volunteers from health and social services. It concludes that further research is needed on how volunteers select coping strategies, and on how the processes of coping with the numerous challenges of providing care can be better supported.


Baylies provides an early account of the impact of caregiving on household economies in Zambia. Drawing on data from the mid-1990s, including surveys with 150 adults, the paper argues that the impact of HIV and AIDS on households has been treated as less urgent than other disasters such as droughts. It suggests that because of increasing marketisation and individualisation of the economy, combined with structural adjustment programmes, care for people living with HIV and AIDS has become privatized in people’s homes and immediate family networks, rending the impact on labour, economy and social structures less visible. Furthermore, the article recognizes that because women primarily provide this care, female-headed households carry a greater burden. Baylies explores possible mitigation strategies and argues for a wide-ranging multi-pronged approach. She concludes that, as the impacts of HIV and AIDS on households are unique, long term strategies that recognize the distinct effects of the epidemic must be developed.


This article focuses on how the relationship between HIV and AIDS and food-insecurity is mediated by gender inequalities, using a case study of the Malawian famine of 2001-2002. Its wider argument centers on whether the concept of New Variant Famine is a useful explanatory tool in understanding the interaction of HIV and AIDS and famine – and suggests it is, as long as gender is integrated into this relationship. With respect to caregiving, the paper argues that because of the socially constructed nature of gender, women provide the majority of care for people living with HIV and AIDS and for orphans.
Because of this, female-headed households have higher dependency ratios (the number of dependants compared to adults), and a greater risk of being food insecure, compared to male-headed households. It also points to the fact that this is mediated by wealth, with richer households less affected than poorer households.


This paper analysis the experience of adults caring for orphans in Botswana. Through a survey of 1033 people, representing the working population of Botswana that access government healthcare in urban and semi urban areas, this study describes households that care for orphans, and the nature of care provided to orphans.

Many caregivers found it hard to balance paid employment and care. Furthermore, many orphans had greater care needs due to poor health conditions, such as HIV infection. Though caregivers needed greater income to provide for care needs, they were often unable to work weekends or overtime because they were demanded in the household to provide care. As a result, adults providing care faced obstacles in meeting both care and work responsibilities.

The study suggests that work place policies need to adapt to allow greater flexibility for those caring for orphans, such as allowing greater amounts of paid care leave, and more flexible work hours. It argues that more flexible policies would be in the best interests of the orphans and of the economy.


This paper discusses the relationship between stigma and care through research with the Leo Toto Outreach Kangemi Program in Nairobi, Kenya. The study has two aims: a) to quantify, through use of an AIDS stigma scale, the level of expressed stigma in the population; and b) to characterize the association between the respondents’ stigma-scale scores and other social beliefs and demographic characteristics.

Participants of the study included clients of the Leo Toto Programme, including 180 households and 873 individual respondents, who participated in questionnaires and surveys. The researchers created a dichotomized stigma scale in order to evaluate the degree of stigma of the respondents, as well as a scale to measure beliefs/knowledge about HIV and AIDS care.

The research found that decreased levels of stigma were related to increased knowledge of care. Concurrently, high levels of stigma were related to decreased knowledge of care.
However, respondents generally demonstrated poor knowledge about the care required for an HIV positive person. The authors conclude that increased care knowledge and support may contribute to the reduction of stigma and vice versa. They suggest this data be used in care/support and stigma interventions.


This paper documents the experiences of 12 households in rural KwaZulu-Natal, South Africa. Through ethnographic observations and case studies of 20 households, where at least one adult had symptoms related to HIV and AIDS, it discusses how illness and death is experienced by households and communities.

The study found households struggled to cope with the daily demands of caring for the ill, caring for orphans and recovering from recent deaths. Most households experienced multiple episodes of HIV and AIDS related illness and death, resulting in an increased dependency ratio. The repetition of illness and death was also found to have psycho-social consequences, which contributed negatively to stigma and discrimination. Furthermore, HIV and AIDS related illness and death was compounded by illness and death due to other causes. Such multiple deaths caused people to move to other household, thus widening the impact in the community. The paper concludes by suggesting more research is needed on how care in the households has an impact on the larger community.

**Kipp, W., et al. (2006) Care burden and self-reported health status of informal women caregivers of HIV and AIDS patients in Kinshasa, Democratic Republic of Congo, AIDS Care, 18(7), pp. 694 — 697.**

This study examines the social and economic challenges faced by women caregivers in Kinshasa, Democratic Republic of the Congo, and estimates the caregivers’ self reported health status. The study is based on semi structured questionnaire with 80 women caregivers, under the age of 50, who were enrolled in a home-based care programme.

The study found that all of the women were caring for their spouses, and that most did not receive care support from friends, families, churches or other groups. The participants attributed this lack of support to stigma. Most found caregiving difficult and stressful. As a result most also reported various degrees of unhappiness, and numerous physical complaints as a result of caregiving. The mean of the self-reported health status score was 9.1.

The study concludes that it has provided a conservative estimate of the caregiving burden experienced by women caregivers, and argues that ‘care for the caregiver’ needs to be a component of all HIV and AIDS responses.

This study looks at the experiences of those providing home-based care in Lesotho, in terms of accessing services and dealing with confidentiality limitations. It points out that maintaining confidentiality is controversial, especially in African contexts where family and community members are responsible for a large portion of the care provision. 21 home-based care providers were interviewed and a phenomenological approach was applied to obtain the perspective and experience of these caregivers.

Results found that in many cases care was delayed because the caregiver was unaware of the severity or nature of their patients’ illness. Caregivers expressed a frustration at being excluded from ‘the patient – doctor secret,’ and those who were able to confirm their patients’ HIV status reported improve care afterwards. Caregivers also expressed frustrations in lack of consistent provision of medications, and poor services at the hospitals and clinics. Specifically, they expressed anger when turned away from hospitals when they felt their patients needed clinical care.

The paper concludes that quality care is based on effective communication between the patient, the caregiver and medical professionals. Confidentiality can undermine this essential communications. It is recommended that health professionals develop ways of dealing with confidentiality and HIV and AIDS care that empower the families and communities who carry most of the care burden.


Recognizing the increasing burden on caregivers, this paper reports on the issues and challenges caregivers face in order to inform home-based care policies and programs. In-depth interviews were conducted with 45 caregivers living in informal settlements near Cape Town, South Africa. Data was analysed using a grounded theory approach.

The study found that caregivers were often overwhelmed by care work, which was all consuming, even when they were provided with useful assistance. Care burdens had negative impacts on caregivers’ mental health. Respondents linked improved care support with improved health status for themselves and their patients.

The paper concludes with four recommendations: 1) Integrating mental health services and community-based care and support for PWA; 2) Integrating a gender perspective in policy on home-based/community-based care and support; 3) Strengthening the capacity of NGOs to manage the psychosocial and gender dimensions; 4) Developing the capacity of household caregivers who want to be trained, and learn from their experiences.

This study examines the mechanism of income loss amongst working adults in Botswana due to HIV infection or caregiving, and the consequences for household well being. It also considers factors that enable economic survival of households. It is based on 254 in-depth interviews with adults attending government clinics.

The majority of respondents reported having had to care for someone who was ill with HIV and AIDS. About a third of respondents reported losing income while caring for the ill, due to having to take unpaid leave, or job loss. Additionally, income was lost when the primary breadwinner died. A primary concern was caring for children on a reduced income.

The study concludes that, while progress is being made towards increasing access to AIDS treatment, a gap remains in providing support to AIDS-affected individuals and families for their economic survival and to meet their basic needs. Public and private sectors need to help address the challenges encountered by HIV infected adults and faced by caregivers in sustaining critical household income, while also meeting health needs.


This paper critically examines the discourse on coping within the context of HIV and AIDS. It argues that, while coping terminology features frequently in studies on rural livelihoods and HIV and AIDS, it obscures the struggle for survival many households face.

The paper outlines some of the literature and theory on coping strategies as concerns famines and disasters, and compares it to the HIV and AIDS context. It finds that households respond differently to HIV and AIDS, than to other events that require coping. Specifically, HIV and AIDS is not seen as a simple short term challenge, as many natural disasters are, but a long wave event. It therefore questions the utility of coping strategies for shaping policy, suggesting they can in fact be used by governments to abdicate responsibility onto communities and households already struggling to survive.

The paper concludes with two questions: 1) When a disaster brings fundamental change in the agro-ecological, social and economic landscapes, can we still talk about coping? 2) When households and communities are barely able to respond to unremitting pressure on livelihoods, is this coping or struggling to survive?

This paper offers insight into the experiences of those providing care for people with stigmatized illnesses, such as HIV and AIDS, in the Caprivi Region of Namibia. Drawing on Amartya Sens’ capabilities theory, it recognizes that social relations are lived through emotions, arguing it is therefore important to not only consider the material realities of caregiving, but also the physiological impacts.

The study applied various methods such as focus groups, interviews and livelihood surveys, but found the use of solicited diaries the most applicable to its topic. The diaries illustrate that while compassion and sympathy toward the ill person was evident in the early stages of illness, over the long term the considerable burden upon households adversely affected livelihood security and intra-household relations. The importance placed upon being self sufficient and contributing to reciprocal support networks often influenced patient care and well-being in the household as caregivers struggled to balance care tasks with other demands. This situation was exacerbated by the terminal and stigmatised nature of AIDS.
Much of this research describes the gendered nature of caregiving, stressing that most care work is done by women. More recently this category has been broken down to look specifically at the role of young caregivers and elderly women. One of the few studies that question this is by Montgomery et al. and suggests that the gender biases of researchers and research participants may obscure the role of men in caregiving. More research is needed on male involvement in, and perceptions of, caregiving.

The articles described here stress that, who caregivers are, in terms of work, age, livelihoods, vulnerabilities and gender, affects the sustainability and viability of caregiving at the household and community level. For example, Chazan and Whiteside explore how the vulnerabilities of elderly female street traders influence their role as caregivers. It is made apparent that the burden of care falls heaviest on those already highly affected by the epidemic, and on those who are also vulnerable to other stressors and insecurities.


This paper explores seven commonplace assumptions about grandmothers and caregiving in South Africa that are typically articulated in academic research and government and international development policies: 1) AIDS is drastically reconfiguring the roles of African grandmothers; 2) it is the primary stress in these women’s lives; 3) AIDS has led to ‘child-headed’ and ‘skipped-generation’ households; 4) grandmother caregivers are old and frail; 5) South African grandmothers’ access to social grants are crucial for social networks; 6) grandmothers are bearing the burden in rural and isolated settings; and 7) the worst of the epidemic is manifest now, as parents and breadwinners are dying.

Chazan argues that these assumptions obscure a much more complex reality for those grandmothers providing care in the context of HIV and AIDS. This includes the fact that many grandparents – even before HIV – were providing crucial levels of care, that there are other factors providing stress to the caregivers, particularly poverty and the fact that many grandmothers are under 60 and therefore do not receive the social grant for the elderly. Importantly, Chazan argues that the simplification of the idea of grandparents providing care has led to misguided policy approaches that mean adequate support structures are not in place.

This paper links an analysis of the HIV epidemic in South Africa with an ethnographic study of street traders in Warwick Junction, Durban. It describes how social transition is impacting vulnerabilities amongst different age and gender groups of street traders. Twenty street traders participated in multiple in-depth interviews, over two years, and the researchers conducted participant observations.

The study finds that older women are dealing with disproportionate effects of the pandemic in terms of providing care to the ill and orphaned. Two thirds of the older women interviewed were caring for someone, and in many cases were caring for multiple people. Older women reported they supported increasing numbers of dependants on shrinking incomes. This placed a large emotional burden on these women.

The paper concludes that the vulnerabilities of street traders illustrate the links between the macro and micro realities of AIDS. It suggests these realities are differentiated by location, age and gender, with older women carrying the majority of the care burden.


This paper explores the roles of men in households affected by HIV and AIDS, and how their roles are perceived by the wider community. It challenges the general gendered assumptions that men do not contribute to care.

The analysis is based on field notes collected over a two year period for a project documenting 20 households affected by HIV and AIDS. The field notes were analysed for all mentions of men, their activities, their roles and perceptions of them. Findings indicate a great difference between how men are talked about and what they are actually doing. Both research participants and research assistants demonstrated biased views of men’s roles, often ignoring or failing to notice men’s participation in care activities. It was found that while common perceptions allowed women to take on breadwinning roles, they did not allow men to take on homemaking roles without being ridiculed or belittled. Home-based care staff from a local NGO was reported to also reflect these gender biases.

The study concludes that while men participated in a variety of activities to support households affected by HIV and AIDS, the dominant discourses about men remained negative, accusing them of abandonment, neglect and irresponsibility. It is therefore important to highlight the positive role of men in communities affected by HIV and AIDS, in order to more effectively challenge gender barriers.


This paper describes the provision of home-based care and health services in Kenyan communities that are experiencing a high percentage of HIV infections. Findings are
drawn from surveys of 1422 households, which were followed up five years later, as well as in-depth interviews with 25 households.

The study found that most ill adults visited hospitals and clinics before their deaths, but that substantially more men received hospital care than women. It was found that this was because women had less access to money to use for hospital costs than men, and that women, as the primary caregivers for the sick did not receive the same degree of care themselves.

This paper highlights the importance of considering the economic and social reasons that prevent women from accessing health services until very late in their illness. The paper concludes with a number of policy recommendations.


This paper argues that care work by young people, though common, is a largely hidden and unrecognized contributor to national economies, and that young people’s care experiences are connected to globalised processes such as the AIDS pandemic. It further builds on the existing theoretical and empirical literature on geographies of childhood.

Young people’s labour is located within the economies and geography of social reproduction. The context of AIDS in Africa is reviewed, with specific reference to economic liberalisation policies, and data from young caregivers in Zimbabwe. The research finds there is a relationship between young caregivers experiences and broader global processes. It concludes that more work is needed on young people’s geographies and unpaid work. Policies need to aim to provide material and economic support to young caregivers, recognizing their work as necessary and important.


This paper seeks to shed light on the often invisible care work of children in the home in Africa. Building on past work on childhoods by population geographers, it also incorporates work from micro-geographies of caring in communities affected by HIV and AIDS. It utilises three studies from communities in Lesotho, Zimbabwe and Tanzania, which apply a variety of quantitative and qualitative methods.

The study in Lesotho found that families may send children elsewhere to care for sick relatives. The study in Tanzania reported on how care burdens affected primary school attendance. Research in Zimbabwe on the social and emotional implications of care giving, found that young caregivers struggled with exclusion and loss of educational
opportunities, but also approached caregiving from a positive, learning opportunity, perspective.

The paper concludes that the work of young caregivers extends beyond ‘normal’ expectations, and that the implications of care giving on their lives are profound. The authors suggest further research on how young caregivers fit into broad care and social structures and processes.


This paper aims to describe the role of older women in providing care to those affected by HIV and AIDS in rural north eastern South Africa. It uses quantitative data from the Agricourt demographic surveillance site and qualitative data with 30 women between the ages of 60 and 75. It examines how older women spoke about their role and describes their experiences in the household.

The study found that elderly women were caring for other vulnerable household members, especially those ill due to HIV and AIDS. However, many respondents were reluctant to call their care work a burden, as they felt they were carrying for ‘their own blood’ and therefore it was a duty. The paper suggests older women may need increased social, economic and emotional support as the epidemic escalates and their care duties increase.


This paper discusses changes in the household structure of elderly persons who care for people living with HIV and AIDS and orphans in Uganda. It discusses the strain care work puts on elderly people’s own health. Data was obtained from in-depth interviews with 27 people over the age of 50.

The majority of respondents reported providing physical as well as emotional care to people living with HIV and AIDS, and had provided care to one or more orphans in the last 10 years. Though both men and women were involved in caregiving, both genders reported that women were more often the care provider. Changes in living arrangements depended on the gender, economic situation and marital status of the person needing care. Many respondents reported having to give up space in their houses or their beds to patients and orphans. Attempts to hide sickness were a common theme in responses.

The study concludes that taking on the role of caregiver causes dramatic changes in the living arrangements of the elderly, which can have an adverse effect on their health.

This paper uses the narratives of older children in Zimbabwe to explore their experiences with the death of a parent due to AIDS. It presents an anthropological perspective on death, noting how loss and grief are experienced is dependent on culture, and that Zimbabwean cultures create unique contexts for experiencing death. The study is based on qualitative research at six sites, where 56 orphaned and 41 adults were interviewed.

The children were living in a variety of arrangements including with relatives, on their own and in child headed households. A common theme that emerged from their interviews was that they felt they had lost their childhood following the death of their parents. Many had taken on significant caring responsibilities during their parents’ illness. Children expressed a desire to ‘know the truth’ about their parents illness, and indicated emotional burdens due to stigma and the loss of their parents.

The paper concludes by noting that further longitudinal research is needed in order to develop a culturally informed understanding of the needs of children who have cared for and lost parents to AIDS.
Social context of care

Research on the social context of care examines the care economy, perceptions of care and illness, and the influence of global shifts in concepts of care. A number of studies look specifically at how government rhetoric and policies influence the social and economic environment of caregiving. For example, Hassim discusses social welfare policy in South Africa, and its inability to effectively address issues of inequality and social justice in terms of the gendered divisions of labour.

Common themes emerge around how social safety nets function within the context of HIV and AIDS, and where such safety nets place the majority of the burden of care. Many studies stress how gender relations at all levels of society impact caregiving and perceptions of care work. More research is needed to further analyse and critically assess how social contexts undermined and/or support caregiving.


This article reports on interviews conducted with caregivers in rural Malawi. Fifteen caregivers, all women, were interviewed. Few of the caregivers identified the illness of their patients as HIV, and none of the patients had been tested. However, HIV was openly discussed in the community and the authors suggest not naming HIV was not a symptom of denial or stigma, but an existential decision on the part of the caregiver. Caregivers provide the basic support of providing food and traditional medicines, cleaning and providing emotional care. Care was generally provided empathetically, and primary caregivers reported receiving additional support from friends and family, though they did the bulk of the work themselves. Many caregivers did not report any burdens or problems, as they felt their role was a duty not to be complained about.

The paper concludes that the social safety net for care is still functioning. The caregivers provided basic and compassionate care, and received some support from the rest of the community. Reluctance to diagnose illness as HIV or AIDS related appeared to have little impact on care. Still caregiving was a burden that weighed heavily on caregivers and contributed to the poverty the community already lived in. The paper makes the policy recommendations that respite care and training should be introduced, but notes that the underlying problems of poverty and the fatal nature of the AIDS are the more challenging issues that need to be addressed.

This paper discusses social welfare policy in South Africa, and its inability to effectively address issues of inequality and social justice. Drawing on Amartya Sen’s capabilities approach, it argues that a focus on social sector spending is an inadequate approach to addressing inequalities, especially gender inequalities. Hassim argues policies are both socially and institutionally embedded, and therefore poor state infrastructure results in communities becoming shock absorbers for social crisis, increasing gender burdens.

In the context of HIV and AIDS, Hassim notes that the Expanded Public Works Programme, which promoted the formation of home-based care and child care programmes, had the potential to recognize and address unequal gender divisions of labour. However, the policies fell short of these goals, and due to poor implementation, did not benefit those in need.

The paper concludes that women’s inclusion in the democratic process has not had the anticipated outcomes of increasing gender equality or addressing the gendered division of labour. The failure to build an adequate health system has shifted the burden of care onto women.


This paper reviews issues related care in the context of HIV and AIDS, arguing that a care economy provides a useful lens, which illuminates that increased labour and other demands place on households. It argues that while some strides have been made in supporting care for those affected by HIV and AIDS, much more needs to be known and done. The care economy is defined as the unpaid work, within the home and community, to provide physical, social and psychological support. This work, often done by women, is crucial to the paid economy, though it often remains invisible.

The paper describes how the care economy lens helps distinguish between care provided in the home, care provided by volunteers, and care that is linked to other programs or support services. It argues that unlinked caregivers face numerous challenges such as the risk of burn out, lack of resources and feelings of despair. Since the increase of HIV infections, health systems have struggled to meet care needs. Furthermore, many people do not, for various reasons, access formal health services. This has placed an additional burden on homes and communities to provide care.

The paper argues that while programmes and policies are emerging, further work needs to be done. It suggests two key areas where further policy intervention and development need to take place. The first relates to the ‘international care agenda’, emphasizing an increased focus on the caregiver. The second issue relates to the need to develop comprehensive national frameworks to ensure caregivers are adequately supported by public, private and NGO service providers.

This paper places the current generation of community health workers (CHW), in South Africa, within the broader history and policy context of CWH, focusing on their role within the response to the HIV and AIDS pandemic. It analyses the policy context and then reports on the role of CHW in the Free State Province in South Africa. It is part of a larger, longitudinal study to document the implementation of anti-retroviral treatment (ART) roll-out in Free State Province. Research methods include analysis of policy documents and field visits to primary health care facilities that were rolling out ART.

The paper discusses the opportunities, tensions and challenges of community health workers within the health system. It finds that CHW play a crucial role in health services, and that many HIV and AIDS programmes would not be possible without them. However, CHW remain on the margins of health systems, filling an ambiguous role as volunteers/workers. The article concludes with a number of recommendations to better incorporate and support CWH as a component in the response to the HIV and AIDS epidemic.


This study surveys HIV and AIDS projects implemented by local governments in South Africa. It analysis these projects, discusses opportunities and challenges, and suggests ways to strengthen local government responses. The contacted municipal governments for information about their HIV and AIDS programs. Forty-four municipalities replied to the questionnaire sent out.

Results indicate that most programmes focused on prevention, not care and support. However, the study predicts this will change as the infection rate peaks and the need for treatment increases. Funding for budgets was identified as serious project constraints. However, under spending at a provincial level was also reported as a problem. The researchers suggest more needs to be done to involve the private sector in HIV and AIDS projects. Furthermore, municipalities face numerous challenges incorporating HIV and AIDS into their integrated development plans, due to lack of capacity. The paper concludes that, as local governments are likely to be the focal point of the response to HIV and AIDS, both the government and the private sector need to channel resources and support towards municipalities.

This paper examines the social protection policies of South Africa within the context of HIV and AIDS. It argues that the nature of poverty has changed due to the AIDS pandemic, exposing gaps in social protection policy, especially as concerns access to education and health care.

The paper begins by describing the shift from concepts of social security to those of social protection. It then looks at how HIV and AIDS affects the meta dimensions of poverty, arguing HIV and AIDS responses need to be both immediate and long term focused. It suggests that there is already ample evidence of the gaps in social protection policies’ responses to HIV and AIDS, and explores these findings in detail. It suggests that HIV and AIDS allows us to see the holes within the social safety net, creating an opportunity to reform social assistance within South Africa.

The paper concludes by arguing that responses to HIV and AIDS have tended to be short term and fail to understand the complexity of the pandemic, which traps people in chronic poverty.
Interventions to support caregivers

Case studies from specific projects provide the bulk of the research on interventions to support caregivers. For example, Esu-Williams, et al. describe a project with young caregivers in Zambia, and Mabude, et al. examines the provision of home-based care kits in South Africa. Such case studies provide perspectives on localized and specific interventions. They often analyze weaknesses in support systems and projects, and generally conclude with policy recommendations.

More theoretical analysis is provided by a number of studies by Campbell and others, which describe the links between support interventions, community power structures and broader social contexts. The role of various actors - such as government, non-governmental organizations, churches, community members and family - in providing, or failing to provide, support to caregivers is described and lessons learnt for future interventions are shared.


This paper presents a case study of a community response to HIV and AIDS in rural South Africa in order to gain understanding of how social environments support and/or hinder the coping mechanism of people affected by HIV and AIDS, and how best to support community responses. The research presented is the first step in an ongoing project, which aims to promote social environments that are supportive of people living with HIV and AIDS and their caregivers. The researchers conducted 45 in-depth interviews and 15 focus groups with a range of local residents.

The participant community is extremely rural and 30 kilometers from the nearest town or health facility. Research findings indicate the multiple needs of people living with HIV and AIDS and their caregivers, such as the basic necessities of water, food and medicine are not easily met. Furthermore, the community faces multiple challenges within the social environment. For example, the church network is resistant to addressing HIV and AIDS, and public sector support services are described as inadequate and unsympathetic. Volunteer health workers provide the majority of support to those affected by HIV and AIDS, often despite many challenges.

The paper concludes by questioning how to facilitate a more effective response to HIV and AIDS in the community. It suggests there is a need to facilitate a formal partnership between the various community actors, while recognizing the complex role of many of these actors in being both potential facilitators and inhibitors of an effective community response. As an outside change agent, the researchers hope to be able to be the impetus for development, which many community members note is currently lacking, by building on already existing community resources and activities.

This paper is based on the experience of the Centre for HIV and AIDS Networking in developing a three year volunteer home-based care programme in rural KwaZulu-Natal, South Africa. The project aimed to apply a participatory approach, taking into account the specific social and cultural dimensions of the community. It utilised the AIDS competent community framework in setting and implementation, and used a qualitative, social constructionist approach to research. Data was collected from 17 discussions (focus groups and interviews), with a total of 34 community members, in order to seek out community perceptions of the program.

The programme sought to improve the skills and knowledge of home-based care volunteers. It further aimed to improve local and external support to the volunteers. Results indicate that while the project met its target related goals (such as increasing the skills and confidence of volunteers); it did not meet its empowerment related goals (such as fostering community ownership for addressing HIV and AIDS or promoting democratic project management). The paper concludes that without support from local and external actors, such projects are limited in their ability to address the underlying factors influencing the epidemic, such as poverty and gender inequality.


This paper reviews existing research on home-based care and discusses how researchers can continue to contribute to the development of more effective home-based care programs. The review includes work from PubMed/ MEDLINE, the International Bibliography of the Social Sciences, and abstracts from the 2002 International AIDS Conference in Barcelona.

It notes most of the research is descriptive and fragmented. Common themes include descriptions of the challenges caregivers face, and the difficulty of creating enabling social environments for effective home-based care. The review divides the literature into those studies that focus on individuals, households, families and communities. It notes that most studies refer to the need to develop social partnerships and collaborative efforts. More work is needed on the role of traditional leaders. Furthermore, while most research addresses the challenges of home-based care, there is a great need to develop an understanding of which partnerships facilitate healthy environments, and how such environments can be developed. It suggests that the social capital framework may be a useful starting point for this task.

This study concludes that more work is needed in the following areas: examining which forms of social capital have the potential to assist local communities in meeting each of these challenges; conducting systematic research into the evolution, the nature and
effectiveness of different partnership strategies; and developing understandings of the factors which promote or hinder the success of different types of alliances/ linkages.

Esu-Williams, et al. (2006) ‘We are no longer called club members but caregivers’: Involving youth in HIV and AIDS care giving in rural Zambia. AIDS Care, November 18(8), pp. 888-894.

This paper reviews an intervention study which aimed to build the capacity of youth involved in anti-AIDS clubs in Zambia in providing home-based care. The study determines what caregiving roles young people were able to fill and how young people would respond to active involvement in caregiving.

Twelve local health professionals trained 300 youth from 30 clubs. A local advisory committee was established and youth were provided with home-based care kits. Data was collected from two cross-sectional rounds of interviews, surveys and focus groups of club participants, family and community members.

Research found that anti-AIDS club members were eager to learn, develop new skills and volunteer. They were capable of providing quality care, and demonstrated an openness to explore traditional gender norms. However, they faced frustrations in being unable to provide for the material needs of their patients. The study suggests young caregivers require increased monitoring and encouragement, and that building local linkages with other service providers is essential. A follow-up study will address the sustainability of the project.


This study assesses the delivery of home-based care kits in South Africa, in order to discuss the feasibility of scaling-up provisions. The researchers contacted all home-based care kit providers in the country who had contact information. 215 organizations completed the questionnaire provided. Five organisations per province were randomly selected to conduct key informant interviews. Interviews were also conducted with provincial community coordinators and companies that supply or distribute home-based care kits.

Results indicate that organizations adapted kit contents to fit their needs and resource constraints. Kit provision was dependent on government and other donor supply, and was unstandardized and inconsistent. Most organizations reported that they did not have enough kits, and caregivers had to frequently share kits and sometimes had to do without. Most organisations only used lay kits, though a few used professional kits. In most cases caregivers brought the kits with them to the households, only leaving it there in a few cases.
The study concludes that simple and more affordable kits are needed to increase access to kits by end users. Organizations providing kits face numerous challenges, and many expressed frustrations at not being able to provide quality care to their patients. Projects struggled for sustainability because they were dependent on government and donor funding. Improved delivery and supply is needed, as well as effective monitoring and evaluation. A discussion amongst stakeholders following the study echoed these findings.


This study examines the sexual behaviour, contraceptive use and unmet need for family planning amongst home-based care providers and clients in Kenya. Based on interviews and focus group discussions with home-based care program participants (171 clients and 183 caregivers) in Nairobi and in Western Kenya, this paper describes the perceptions and challenges HIV positive women, and caregivers, experience in family planning.

The study found that home-based care clients and providers were less likely to have an unmet need for contraceptives than the general population. Community members reported that there was overwhelming stigma directed at HIV positive women who decided to have children. The study concludes that counselling efforts to promote consistent condom use is imperative. There is also a need for counselling support for women who wish to get pregnant. However, before increasing efforts to provide contraception options to women and provide adequate counselling, home-based care programs need to take their current resource limitations into account.


This article reports on a project in rural KwaZulu-Natal, South Africa, which sought to build partnerships in order to facilitate a grassroots response to HIV and AIDS. The project seeks to break down traditional distinctions between users and providers in health services, arguing grassroots responses have better chances of success if they see communities as equal partners in the process. It seeks to support the community to develop a health enabling social environment.

The paper describes the formation phase of partnerships within the project, drawing on meeting notes, interviews and discussion groups. It outlines challenges and opportunities for working with public and private partners in the community. It then discusses the role of the project as an external change agent, concluding that there are numerous challenges to building partnerships, especially with the public sector. The most potential for partnership was found to be with two small NGOs. Additionally, community support, through voluntary health workers, appears to have potential. It suggests adding the
following criteria to the effective partner list: moral, confidence, and institutionalisation. The paper contributes to other qualitative studies on partnership building within the HIV and AIDS context.


This study was undertaken across seven sites in South Africa, where the South African Hospice Association had implemented home care using the integrated community care model. The research aimed to learn more about how community caregivers perceived their work, the components and intensity of their work, and the supervision that they received. Community care giving sites were visited twice over 18 months, community caregivers were individual interviewed, and statistical data was analysis.

The study found that much of the work of community caregivers including advising, informing and counselling. The caregivers were satisfied with the support they were provided with, however supervision was not properly developed. Caregivers visited, on average, 43 patients per month, selecting those most in need. The study recommends more comparative studies on community care giving are needed.
Care and ART

As the delivery of anti retroviral therapy (ART) is relatively recent in southern and eastern Africa, very little research has been completed on how care is changing as increasing numbers of people access treatment. As people on ART live longer, face challenges to adhere to their medication regimes, and reenter the labour force care needs change. At the same time, stigma, emotional burdens, and illness due to side effects – as well as eventual terminal illness - remain a reality for people on ART and for their caregivers. How care is changing due to ART, and how to support caregivers in this new context remains under researched.


The introduction of ART in Zambia is changing the home-based care needs of people living with HIV and AIDS. This short article describes how patients who were previously bed ridden have become active again, since starting ART, and so are in need of different types of care. Instead of palliative care and end of life counselling, they may need positive prevention information and adherence counselling. They may also be well placed to take part in income generating activities. This paper concludes that if home-based care programmes do not adapt quickly to these new needs, people living with HIV and AIDS may not have the support they need to adhere to medications, and therefore carers will be once again tasked with palliative care.


Weak health services and systems in Africa are often presented as barriers to adherence to antiretroviral therapy. As such alternative delivery mechanisms – such as, decentralisation of clinics and delivery of medication through home-based care programmes – have been explored.

This paper discusses the possibility of using a home-based care programme to achieve high levels of adherence to antiretroviral therapy in Uganda. The researchers enrolled 987 treatment naïve patients into the programme over one year. Adherence interventions included group education, personal adherence plans developed with trained counsellors, a medicine companion, and weekly home delivery of antiretroviral therapy by trained lay field officers. At the end of the study the researchers found high levels of adherence to antiretroviral medicine through measuring the viral load of patients in the cohort. They argue that home-based care programmes provide an effective way of providing treatment in situations where health systems may be inefficient.