Caring for people living with AIDS

A labour of love

Corrie du Preez & Anke Niehof

This paper discusses the concept of care and its implementation with reference to caring for people living with AIDS (PLWA) as 'a labour of love'. The first part of the paper elaborates on care as love, an emotion, and care as labour, an activity, followed by a discussion on four interconnected phases of care, namely 'caring about', 'taking care of', 'care-giving' and 'care-receiving' and the requirements for 'good' care. The gendered nature of care and the resources required for adequate quality care are also discussed. The emphasis in this paper is on the arrangement of care for PLWA, at the micro-level of the household as provided by family and community members, while recognising the role of the state and the market in care provision. This framework is applied to cases from non-urban KwaZulu-Natal in South Africa. The cases, presented according to the four phases of care, not only illustrate care for PLWA as emotion and hard work, but also reveal the gendered nature of care and the resources required to provide quality care. The discussion, the last part of the paper, reflects on care as emotion and care as work and what it entails for different gender groups in this cultural setting characterised by limited access to especially economic resources, where social capital proved to be a crucial resource for the PLWA to access care. It also goes beyond the four phases of care by incorporating the experiences of the caregiver and her/his response to the feedback received from the care receiver.

[care, love, AIDS, gender, social capital, South Africa]

Introduction

Care as 'labour of love'

In general terms, with reference to the Oxford dictionary, caring can be described as "feeling concern for, and taking charge of, the well-being of others", says Graham (1983: 13) in the book *A Labour of Love – Women, Work and Caring*, edited by Janet Finch and Dulcie Groves. Hilary Graham refers to care as 'a labour of love'. This phrase captures two important elements of care: care as an emotion and care as an

activity. The phrase 'care for' is sometimes used as an alternative to the word 'love', where the latter may seem inappropriate to express how one feels about family, friends, or acquaintances. "Although a universal need, only certain social relations are seen to facilitate the giving and receiving of care" (Graham 1983: 15). Frequently these caring relationships involve women, a mother, daughter or wife, and are associated with the private sphere of the home, household and family where informal care-giving takes place. Men have more access to the public sphere where solutions to problems of care arrangements can be found. Women's reproductive role lies at the basis of this division of labour, the assignment of women to the private domestic sphere, and hence, the vision of women as 'natural' care givers. The key to seeing caring as women's work lies in an understanding of the nature of the family. In the first place, caring by mothers is identified as the process by which the construction of gender takes place, while in the second place, caring by wives and mothers is the mechanism by which families are reconstituted on a daily basis (social reproduction). The family unit, in turn, provides the structure in which caring is carried out: "in which children are nurtured, husbands sustained, and the elderly and handicapped supported" (Graham 1983: 23). This caring role of women also extends outside the home to caring professions such as nursing and social work, dominated by women.

The fact that care has these two dimensions has two implications. *First*, if care is emotion (love) it means that it is relational; there is always a social relationship involved between the object and the subject of care or the caregiver and the care receiver. *Second*, if care is an activity (work) it means that resources are needed to carry it out. Care work includes a range of activities, depending on the condition of the care receiver, and requires access to and utilisation of a variety of resources. At the very least care requires time and the expenditure of human energy, but usually also tangible resources. In the same book, Rimmer discusses the costs of care. Home-based care is seen as a more cost-effective alternative to institutional care, mainly because family caregivers are not compensated in any way for their work. Rimmer (1983: 131) refers to this as the private costs of care, which include both direct costs, in terms of additional expenses, as well as opportunity costs, a large part of which is loss of income when carers are forced to give up employment.

Phases of care

The approach to health care presented in this paper is largely based on the framework by Joan Tronto, presented in her book *Moral Boundaries – A Political Argument for an Ethic of Care* (1993). The word 'ethic' in the title shows that Tronto sees care as a moral issue. But also to Tronto care is not just a disposition or emotion but also an activity. All these meanings of care are taken together in her definition when she refers to care as a kind of activity "that includes everything that we do to maintain, continue, and repair 'our world' so that we can live in it as well as possible." She sees this 'world' as including "our bodies, our selves, and our environments, all of which we seek to interweave in a complex, life-sustaining web" (1993: 103). It is a very comprehensive description that includes care as maintenance and as restoring or healing,

and not only of our selves but also of our environment, including our social environment, with social relations being part of our world.

Care may take the form of emotional care (as between close friends, spouses, parents and children) or instrumental care (helping somebody with activities that this person cannot carry out him or herself). Health care is both emotional and instrumental. Care is embedded in societal structures, norms and morality, and based on values that underpin the "life-sustaining web". Starting from her comprehensive definition, Tronto develops a framework in which she distinguishes four phases of care and relates these to distinctive requirements. When these requirements are not fulfilled care is not adequate. The framework can be made operational to yield standards for good care. The moral dimension of care is not only in the disposition or emotion but also in the way the different phases of care should be carried out. The four phases of care and the requirements associated with them are summarized in Table 1.

Table 1 The framework of care (Tronto 1993)

Phase	***Requirement***
1. *Caring about* – the recognition that care is necessary, identification of care needs (relates also to social consciousness)	*Attentiveness* – not be self-centred and looking the other way or turning a blind eye or deaf ear (not saying "I didn't know", while you could have known)
2. *Taking care of* – feeling responsible and doing something about it	*Responsibility* – taking responsibility, not just seeing and leaving it to others
3. *Care-giving* – directly meeting the needs for care by physical work in face-to-face contact	*Competence* – care-giving should be done in the right way, quality of care-giving is at stake here
4. *Care-receiving* – acknowledgement and feed back by the person receiving care	*Responsiveness* – allows for assessing the adequacy of care as perceived by the care-receiver
All phases	*Integrity* – the phases should be linked into a well-integrated care process

The word phases implies follow-up. You are only going to 'take care of' a care need if you (want to) see it (care about), and without somebody taking care of the problem there will be no care giving. Adequate care thus requires attentiveness in identifying care needs, taking responsibility for care needs, making sure care-givers are competent, and finding out how the care-receiver experiences the care. It may, or may not be the same person caring about, taking care of and giving the actual care, but phases should be well integrated to provide quality care. All phases of care include an emotional component or require 'love'. Without 'love' one will not see the problem and be motivated to take the action required. In the fourth phase, 'love' enables perceiving the care receiver's experience of the care.

Care is gendered. Because of its association with the private sphere of the household and the family, where care needs arise and are initially responded to, it tends to be seen as a female activity. Care giving is also part of social reproduction. Although the actual balance in the division of reproductive and productive labour between the sexes

differs according to time and place, it is universally skewed, with women dominating in reproductive labour (Niehof 2004). Good care requires a variety of resources, including time and human and material resources. Scarcity of resources may generate conflict in care, as does the cultural diversity in the notions of what constitutes good care (Tronto 1993).

Care and social capital

Because care involves social relations, social capital is important for both care receiver and caregiver to make care-giving possible. Sara Ferlander (2007) argues that different forms of social capital are important for health. These different forms of social capital include bonding social capital (horizontal ties with friends or family with similar social characteristics), bridging social capital (horizontal ties with people with different social characteristics), and linking social capital (vertical ties with people with different hierarchical positions). These horizontal or vertical ties may be strong, or weak, which influences access to care. Ferlander cites empirical studies of a positive relationship between social capital and health. The question is whether the different forms of social capital have a different meaning for the different phases of care from the perspective of the care receiver.

Table 2 Linking phases of care to social capital

Phase	***Type of social capital***
1. *Caring about*	You need to have especially *bonding social capital* for others to recognize your problems. If you don't have close and strong ties your needs may go unnoticed.
2. *Taking care of*	For people to take care of the problem it helps if they have *bridging* and *linking* social capital, or if they can use the *bridging* and *linking* social capital of the patient.
3. *Care-giving*	Actual care-giving if not in an institutional (formal) setting is something you need *bonding social capital* and *strong ties* for.
4. *Care-receiving*	Depends on the relationship between caregiver and care-receiver (see 3).
All phases	For a well-integrated care process you need all forms of social capital.

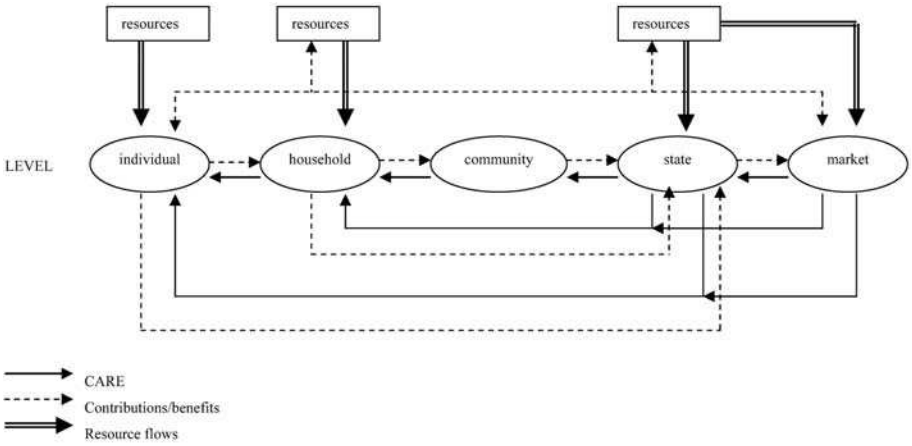
'Caring about' in a more general sense requires exposure to the world around you, whether it is the small world of strong and horizontal ties or the bigger world of the weak and vertical ties. It seems problematic to expect from people who are poorly embedded in social networks of whatever kind that they care about others and the world around them. 'Care-giving' in an informal setting draws on the strength of close relationships and on the moral underpinnings of such relationships. In families, norms about kinship obligations (between spouses, siblings, parents and children) structure the expectations people have of each other and the legitimacy of the claims they make on each other. However, such norms function as guidelines, not as a blue print (Finch & Mason 1993). Close ties create moral obligations and expectations of care-giving that

are – especially in the case of family – based on strong societal norms and values, the principle of reciprocity playing a role as well. However, there are limits to the capability, resources and competence of informal caregivers in the own close social network. When these limits are reached professionals and support agencies have to take over, which requires a new assessment of the situation and somebody else taking care of it.

Micro-macro linkages

Several institutions at different levels are involved in care provision. Care is provided by family members in the private sphere of the household, but also by the community, including neighbours and community health workers, by the state, mainly through public health clinics and hospitals, and by the private sector or market which – in the case of South Africa – includes traditional health care. Although the emphasis in this paper is on the micro-level of the household where home-based care is provided essentially by the family with assistance from community-based health workers, linkages with other levels of care, including the state and the market should not be overlooked. Gradually the state or public sector has taken over forms of care provision that formerly took place in the private sphere. The micro level, however, remains the starting point. Only when care needs exceed the resources, capabilities and competence of the household and family, other actors, such as health workers, various types of professionals, specialized institutions, the state or the market, step in or take over. Figure 1 provides an illustration of the connections between the different levels at which care is provided and the flows of resources, contributions and benefits. Care by the state includes, for example, social grants and hospitable supplies, while the state derives its resources from taxes and premiums. At the household level care is provided to individuals, for which household resources are mobilized, and individual household members contribute labour or money to the household and have their own human resources.

Figure 1 Model of care arrangements



Source: Niehof (2002: 184).

The conceptualization of care as outlined above was applied to assess the quality and limitations of informal care as provided by the household and the community for people living with AIDS (PLWA) in rural KwaZulu-Natal, South Africa.

Methodology

Research area

The research was conducted in a non-urban area in the North-East of the province of KwaZulu-Natal, an area under tribal authority, with 98 percent of the population being Black African and Zulu-speaking. Although only a short distance from a big town, parts of the area lack proper infrastructure; 66 percent of the households do not have access to piped water at the homestead and 39 percent has no toilet facility. The average household size is 5.2 and households are family-based, but may include non-related persons. The research area is also characterised by unemployment and poverty, with only 11.2 percent of the population being employed, the majority of them in low-paying unskilled or semi-skilled occupations. Many households depend for their income on social grants only or a combination of social grants and part-time or temporary employment. Approximately 25 percent of the households in the area do not earn any regular monthly income (Statistics South Africa 2001). The HIV prevalence in the area is approximately 34 percent (DOH 2007). Tuberculosis is also a relatively common chronic illness, with at least 60 percent of those with TB estimated to also be HIV+ (WHO 2007). The lack of proper sanitation at many homesteads contributes to poor hygiene, causing additional health problems and making caring for people with AIDS and other chronic illnesses difficult and time-consuming. Unemployment and poverty may render chronically ill persons and their caregivers unable to access formal health facilities (Uys & Cameron 2003).

Data collection and analysis

Qualitative data were collected between October 2006 and March 2007. Eleven community-based health workers, including eight paid community health workers and three volunteer home based carers, were interviewed and six of them accompanied on several home visits to people living with AIDS (PLWA) and other chronic illnesses such as tuberculosis. Home visits provided the opportunity to interview PLWA, in this paper referred to as clients, and their primary caregivers. Home visits also provided an opportunity to observe care activities performed by primary caregivers and health workers. Data were collected using semi-structured interviews and observation schedules. Ten households were selected based on the willingness of clients and caregivers to participate in the research. Where possible, these homes were visited two or three times over the period of six months to allow for assessment of care over time as the condition of clients changed. A research assistant, fluent in Zulu language, assisted with interviewing and recording of observations. The qualitative data were analysed

by close reading of the notes of the interview responses and observations, followed by categorising, integrating and summarising the information according to themes.

Evidence relating to the four phases of care

Phase 1, caring about

> "He is my son, I have to take care of him. Who else will? He doesn't have a wife and in our (Zulu) culture, another woman may not look after him."
> (65 year-old widow taking care of her 31 year-old unmarried son)

> "I love her, she is my only child. I thought she would take care of me when I am old, now she is sick and I take care of her. I cannot ask somebody else to take care of her, not with this illness."
> (54 year-old mother taking care of her 31 year-old daughter)

> "I worry about the people who live on their own, with nobody to take care of them. I care about the sick people in my community. I want to see them get better."
> (44 year-old female volunteer home based carer)

> "There are many sick people and orphans around me. I want to make sure that they are well taken care of."
> (52 year-old female paid community health worker)

Statements by family members and health workers such as these illustrate how care needs are perceived. Whether it is a family member, a friend, a neighbour or somebody they hardly know, people are generally sensitive to the needs of others. Occasionally, the need for care is also perceived by formal care institutions, such as the local public health clinic, and then communicated to community health workers, to 'take care of'. The person perceiving the need for care or 'caring about' may not be the same as the person arranging the care or 'taking care of', though more frequently than not, the one 'caring about' is motivated to at least 'take care of' as illustrated in the next section.

Phase 2, taking care of

This section describes who 'takes care of' and what it means to 'take care of' or make arrangements for care-giving. Characteristics of caregivers and care receivers of the ten households visited give an indication of the socio-economic position of each, outlined in Table 3. The condition of PLWA in the second column provides an indication of the care they may require, while the relationship of caregivers to care receivers is indicated in the last column. Implications of care arrangements for living arrange-

ments of PLWA and their primary caregivers are also illustrated in Table 3 for some of the households. Table 3 thus provides and indication of who will take primary and where necessary secondary responsibility for 'care-giving' and how these arrangements came about.

Table 3 Characteristics of caregivers and care receivers and their relationship

No	*Characteristics of care receiver (client)*	*Condition of PLWA (client)*	*Characteristics of primary caregiver(s)*	*Relationship of caregiver to care receiver*
1	Female (47) head of HH*, living with children and grandchildren, had to stop income-generating activity due to illness.	Very ill, but her condition improved slightly following treatment for TB and taking of 'boosters'*.	Female (23) with her two children, temporarily left homestead of partner to move back to homestead of her mother to take care. Social grants as only source of income.	Daughter
2	Female (25) living with her two children at the homestead of her parents.	Condition deteriorated, bedridden	Female (48) married, living with husband who is working, another daughter and some grandchildren.	Mother
3	Female (31) lived with her son at the homestead of her mother and aunts. She stopped working in March 2006 due to illness.	Bedridden, passed away at home December 2006.	Female (54) she was working in a nearby town but had to stop working to take care of her only child. Her sister living with them is working and they receive some social grants.	Mother
4	Female (39) lived with her children at her own homestead, moved with youngest children to live with parents nearby when condition her deteriorated. Social grants as only source of income.	Bedridden, passed away in hospital December 2006.	Female (68) pensioner, living with pensioner husband, and two orphaned grandsons. Their other daughter went to stay with the children of the ill daughter.	Mother
5	Female (42) lived with partner and adult son.	Very ill, passed away at home November 2006.	Male (40+) employed, cared for her after hours. A neighbour/volunteer health worker cared for her during the day.	Male partner & neighbour/ health worker

6	Female (40) head of HH living with partner and adult daughter, her son stays with his grandmother.	Very ill, but her condition improved following treatment for TB and starting ARV treatment.	Male (35) employed, cared for her after hours Daughter (22) pregnant and unemployed, took care of her during day with assistance from volunteer health worker.	Male partner & daughter/ health worker
7	Female (23), live on her own after sending her 5-year old daughter to live with family of boyfriend. Not working, gets some money from a brother.	Ill, her condition remained unchanged.	Neighbours know her HIV status and take care of her when necessary, assisted by volunteer health worker.	Neighbours/ health worker
8	Male (31), unmarried, not working, living at homestead of mother.	Very ill, but his condition improved following treatment for TB.	Female (65) pensioner, widowed head of the household, live with sons and their families.	Mother
9	Male (14), living with mother, has not been to school for several months due to illness.	Very ill, but his condition improved sufficiently following treatment for TB and taking of 'boosters' for him to return to school in Jan.2007.	Female (31) head of HH, living with male partner and her two children, works in nearby town. Takes care of son after hours. During the day the volunteer health worker, living next door, took care of him. Occasionally his grandmother.	Mother & health worker/ grandmother
10	Male (31), unmarried, living on his own since his grandmother passed away earlier in 2006.	Very ill, his condition remained unchanged.	Neighbours and paid health worker take care of him. Occasionally a family member comes to stay with him for a short while, but provides little assistance with care.	Neighbours/ health worker

* HH = household

* Boosters = a combination of vitamin and mineral supplements provided by the public health clinic

Source: Interviews and observations Oct 2006 – March 2007.

Where PLWA reside with relatives or partners, or have relatives living nearby, it was always the same person who perceived the need for care who made the arrangements for care-giving, many of them becoming the primary caregivers themselves. Frequently the close relative is the mother of the PLWA residing at the same homestead (see Cases 2, 3 and 8). Occasionally there is not an appropriate person at the homestead to take care of the PLWA, in which case either a relative living nearby has to move in with the ill person (see case 1) or the ill person has to go and stay at the homestead of a relative (see Case 4). Where a PLWA live on her/his own (see Cases 7 and 10) the need for care was frequently perceived by a neighbour and then communicated to a health worker to 'take care of'. When family cannot be located to provide the actual care, the health workers then may approach the same neighbours, as in both these cases, to assist with care-giving. When an ill person has to stay alone at home during the day while the primary caregiver is at work, the community health workers may provide care during the day themselves or again arrange with neighbours to do so (see Cases 5, 6 and 9). Family members who are primary caregivers themselves may also approach other relatives or neighbours to request assistance with care. Most of the time this will only be for respite care, where the primary caregiver need to leave the home for a while, but it may also be because they need assistance with a care activity, such moving a PLWA from a bedroom to a sitting room, as referred to in the next section. More often than not, the person to 'take care of' is also the person to give the necessary care.

Phase 3, care-giving

Care-giving implies physical involvement, work. Table 4 provides an overview of the kind of work that is done and the resources required to carry out the activities effectively. In column one, the activity category, followed by a description of what it entails in column two, with an indication of the resources required in column three.

Table 4 Care activities and resources required

Care activity categories	*Description of activities*	*Resources required*
Monitoring condition	Regular assessment of the condition of the PLWA and when necessary arranging for patient to go to a formal healthcare facility and accompanying the patient.	Knowledge, assistance from health workers.
Basic nursing care	Treating minor symptoms and pain relief.	Knowledge, skills and basic medical supplies including rubber gloves, dressings and ointments.
Physical care	Feeding, grooming, bathing, assist with use of toilet, turning and lifting the patient, assist with walking, etc.	Money, skill, assistance from another person, clean water, supplies such as adult nappies and plastic bed covers.

Treatment	Collecting treatment, supervise or assist with taking of treatment, preparing traditional remedies, etc.	Money, transport, environmental resources (herbs).
Rehabilitative care	Assisting the patient to do some exercises and massaging to prevent/reduce stiffness and pain.	Knowledge, skills, physical strength or assistance from somebody else.
Psycho-social and spiritual support	Talking or reading to the patient, keeping him/her company, spiritual guidance and dealing with nearing death.	Mainly time, but also dedication.
Household assistance	Assistance with domestic work such as cleaning, laundry, preparation of meals, shopping and childcare.	Money, cleaning agents and equipment, water, special foods.

Source: Interviews and observations Oct 2006 – March 2007

All activities at the very least require time, human energy and patience, and can be carried out more effectively with relevant knowledge and skills. The majority of activities though also require social capital or resources, such as assistance from a neighbour; financial resources, to access treatment and supplies; environmental resources, such as clean water; and material resources such as basic medical supplies. All the households described in Table 3 are visited by volunteer or paid community health workers on a regular basis and more frequently when the clients are bedridden. Apart from providing practical assistance with care-giving, they also share their knowledge and skills with primary caregivers enabling them to do their work in a more time and cost effective manner.

The activities which need to be carried out by caregivers depend on the condition of the PLWA, whether he/she is still able to do something for him/herself or bedridden and completely dependent for all activities on a caregiver. Caring for a PLWA who is bedridden and completely dependent is a full-time job, day and night, and thus very demanding if there is only one caregiver. It is also more time and energy consuming to carry out an activity, such as feeding, when the person is very ill and sometimes unable to cooperate with the caregiver.

Phase 4, care-receiving

PLWA are very aware of their helplessness and extreme dependence on their caregivers, some of them feeling guilty because they cannot do anything for themselves. They also experience the physical discomfort of being unable to, for example, go to the toilet on their own, which may make them impatient and demanding. Some of them also do not want to be left on their own demanding the constant attention of their caregivers. Outcomes of care activities are not always positive or successful leaving not only the care receiver dissatisfied, but also resulting in frustration of the caregiver.

In advanced stages of AIDS-related illness, as was observed in Cases 3, 4 and 5 (see Table 3), the patients experience extreme pain and discomfort which makes them very difficult to care for. They may also at this stage suffer from cryptococcal meningitis, which causes behavioural changes and mood swings, at times displayed as aggression (WHO 2005). In Case 4 this was so severe, that the patient had to be hospitalised where she passed away a few weeks later. The response of care receivers to care may thus result either from their dependence and inability to do anything about their situation, and/or it may be associated with specific symptoms of AIDS-related illnesses in the final stage of the syndrome.

Integrity of the care process

To gain a better understanding of the integration of the different phases of care and the contributions to care of all actors involved, we present four cases from Table 3 in more detail.

Case 2 Zethu

Zethu (25) lives in the household of her parents with her two children. Her older sister with her two children, and the two-year old daughter of another sister who works in the city, also live with them. Zethu's father, the head of the household, works part-time as a labourer. The household's only other source of income is the grants received for four of the children. The household lives in a traditional structure and possesses some assets. The first time I visited Zethu she was on treatment for TB and showed some symptoms associated with AIDS. The TB-medicine is collected every month, free of charge from the local public health clinic, approximately three kilometres away, either by Zethu's mother or by a health worker. When I visited Zethu a few weeks later, the symptoms became more severe. A stroke had left her paralysed on the left side of her body, she was unable to walk or talk and completely dependent. She requires full-time care, provided by her 48-year old mother with some assistance from a local volunteer home-based carer. A month later, her condition improved slightly and she was able to talk and eat again. While Zethu's mother, aged 48, takes care of her, her sister does most of the domestic work and looks after the children. Before Zethu got ill she, her mother and her sister shared the domestic work and childcare. Zethu depends on her mother to take care of all her physical needs, including personal hygiene, dressing and feeding. The volunteer health worker passes by as often as possible, at least once a week, to check on Zethu's condition, her taking of medication and to help her exercise the paralysed limbs.

Case 4 Thembi

Before Thembi (39), became critically ill she lived with her five children in a house approximately one kilometre from the home of her pensioner parents. At the time, a sister of Thembi and two orphaned nephews lived with her parents. When Thembi fell ill with AIDS-related illnesses, she could no longer take care of her home and the children, and her 68-year old mother decided that she had to move to their home. Thembi with, the smallest of her two children, twins aged one, went to stay with her parents, while

her 30-year old sister went to stay with the other three children at her home. Already before the illness of her mother, Thembi's 19-year old daughter assisted with the care of her younger siblings and domestic work. About one month after my first visit, Thembi's health deteriorated and she became aggressive to the extent that her family could no longer take care of her and she had to be hospitalised. At this time her mother took the twins back to Thembi's house and spent most of her time there. A few days later Thembi passed away in hospital. When I visited Thembi's house a few weeks after her funeral, her sister was still staying there with the children, while her mother returned to her own house, only helping out at Thembi's house occasionally. Thembi's two oldest children did not return to school after their mother became ill. Thembi's sister will stay with the children at their house as their guardian. The household live on the childcare grants received for the smallest of Thembi's three children, with some financial support from Thembi's parents, both of whom receive old age pensions.

Case 5 Happy

Until her death Happy (41) lived with her boyfriend and her 21-year old son. She also has a daughter who lives in another town. I saw Happy for the first time at the local public health clinic when she went there to collect treatment for tuberculosis. The next time I saw her a few weeks later, was at her house, a traditional structure in a dilapidated state. By this time her condition has deteriorated and she was very ill and weak as a result of AIDS-related illness, no longer able to take care of herself. Both Happy's boyfriend and her son worked full-time and were thus unable to take care of her. A volunteer health worker visited Happy at her home as often as possible, but because she lived far away, could not go there every day. The health worker asked two neighbours to assist with Happy's care, mainly personal hygiene and feeding, during the day. In the evenings and at night, her boyfriend and son took care of her. The last time I visited Happy before she passed away was less than a month after my first visit to her home and by this time she became agitated and did no longer want to eat. Even though willing, her neighbours could not take care of her anymore as she chased them away when they came to her house. She passed away approximately two weeks after my last visit.

Case 7 Nomsa

Twenty-three year-old Nomsa has been living by herself since mid-2006 when her boyfriend moved out and she decided to send her five-year old daughter to live with her sister. At the beginning of 2007, her daughter went to live much further away with the parents of her boyfriend. When she was living with her sister, Nomsa was able to visit her daughter once a month, now she does not know when she will see her again. Nomsa's parents passed away a few years ago, and she only has the one younger sister who lives with distant relatives approximately 45 kilometres away. Nomsa is HIV+, has tuberculosis and started showing symptoms associated with AIDS-related illness when I visited her for the first time at her home. As a result of her illness and weakness, she was unable to work and her only financial support was a small amount of money she received every month form a distant relative. Nomsa lives in a small one-roomed traditional structure, surrounded by neighbours who knows her HIV status and who are very supportive and

assist her with domestic work, fetching water and cleaning the yard when needed. After her health improved slightly at the beginning of 2007, she was able to get part-time employment as a domestic worker. A volunteer health worker visits Nomsa twice a month to monitor her condition.

Case 8 Thabo

Thabo (31) lives with his widowed mother aged 65, the head of the household, two brothers, a sister-in-law, two nieces and a nephew. Also living with them is a twenty year-old orphaned cousin who has been living with them since she was one month old. Thabo's one brother works in the nearby town. His mother receives a pension and one of the children gets a childcare grant from government. The home is far from town with only a small public health clinic a few kilometres away where Thabo collects his tuberculosis medicine every month. Thabo is also HIV+ and when I visited him at home the first time he was very ill and weak and had come home from hospital a week before. He is taken care of only by his mother as Zulu culture does not allow a sister-in-law or other distant female relative to take care of a young Zulu man. Shortly after my first visit he started intensive treatment for the tuberculosis and his health gradually improved. Thabo already lost a brother because of AIDS. Most of the domestic work is done by Thabo's sister-in-law and cousin, allowing his mother to take care of him. When I visited the home of Thabo again a few weeks later his condition had improved and he was able to walk to the clinic to collect his medication.

The cases show how around every PLWA there is a care arrangement that involves several actors with different roles in the care process. In the cases all actors pictured in Figure 1, except for the market, can be identified. There is a high degree of integrity, partly because often the crucial actor in phase 1 is the same person who takes action in phase 2 and does the actual care-giving in phase 3. Frequently this person is the mother. Integrity is also achieved because 'caring about' (phase 1) does not stop after somebody else takes responsibility or provides the actual care-giving. There is a concern about the situation that is more generally shared. In this way, love and solidarity become binding forces that result in a high degree of integrity of the caring process, confirming Tronto's (1993) point of the moral ethic underlying care. What the cases also show is that it is not only the PLWA who needs care but also her or his dependants (children) and the care-giver, who will need (and is given) the assistance and support that fall within the broad definition of care.

Discussion

Without social capital, family, friends, neighbours and caring health workers, PLWA cannot access care. Somebody needs to perceive the need for care as well as be motivated to do something about it (Ferlander 2007, Nombo 2007). This may be problematic, as AIDS is still stigmatised in many areas in South Africa and the afflicted person may be hesitant to reveal the nature of his/her illness and seek help. It is also

problematic for potential caregivers such as family members, friends and neighbours who may be hesitant to become involved in the care process, frequently out of fear of becoming infected with HIV themselves.

Social capital is not only a crucial resource for the patient, but also for the one 'taking care of' and caregivers. Where the one perceiving the need for care is unable to provide the care-giving him/herself, he or she is still expected to take care of the situation by arranging with family, friends or neighbours to give care. Frequently the health workers are the ones to negotiate for care-giving, where family members are hesitant, or where patients live on their own and neighbours are approached for assistance. Caregivers also need social capital, as they often cannot do all the care work themselves and may need assistance with physically demanding tasks, such as moving the patient from the bed to a chair, or need respite care when they need to attend to other business, such as going to town for shopping. Unfortunately the social capital of caregivers often becomes eroded as they are unable to invest time in maintaining their social relations/ties. Because of the time spent on care-giving, they may be unable to participate in community work or they may not go to church as often, weakening their relationships with friends and acquaintances. The social cost of care thus may be so high that a household is unable to recover from the weakening of its social networks (Donahue 2006; Akintola 2004). Social capital may also serve as an intermediate resource through which one gains access to other resources (bridging resources) such as borrowing money from a former employer to travel to the hospital, as occurred in Case 3 (see Table 3). Although social capital is a crucial resource in all the phases of care, caregivers and care-receivers also need access to a range of other resources provide quality care.

Even informal, usually unpaid, care is not free. To provide adequate quality care, caregivers need to be able to access a variety of resources including financial, human and material resources. For the supply of material resources, like rubber gloves, disinfectant soaps, and protective bed covers, community-based health workers act as liaisons between primary caregivers and formal care institutions such as public health clinics or hospitals to access such resources. Caregivers also need access to financial resources, to cover expenses such as travelling to health facilities or purchasing special foods and supplements. Many caregivers experience also economic stress because they had to stop working to take care of patients and incurred loss of income. This is not typical for the situation in KwaZulu-Natal. The Socio-Cultural Planning Bureau in the Netherlands found that many informal caregivers (*mantelzorgers*) reported that because of their care obligations they could do paid work and seven percent of them got into financial trouble because of that (SCP 2003).

The gendered burden of care is reinforced by cultural rules, such as who is allowed to take care of whom, based on gender and age, in Zulu culture (see Case 8). Married men should be taken care of by their wives or alternatively by their mothers, while single men should be taken care of by their mothers or alternatively by a male member of the family. In general women who are sick should not be seen by men, and can only be taken care of by other women. This pattern was also observed by Hutchings and Buijs (2005) in their research in KwaZulu-Natal. It should though be noted that

in our research we found men willing to take care of their female partner. They were not willing or able to stop working to provide care during the day, but they arranged for alternative care for their female partner during the day and engaged in care-giving themselves after hours.

As observed above, to separate 'caring about', 'taking care of' and 'care-giving' proved to be difficult, especially when the same person is the main actor in all three phases. With a condition such as AIDS phases may also overlap, because AIDS is not a specific disease that will take a predictable course. Instead, persons living with AIDS suffer intermittently from AIDS-related illnesses and the seriousness of their condition fluctuates. When their condition takes a turn for the worse, somebody has to see that (phase 1) and take responsibility (phase 2) for adjusting the care arrangement, with in some cases hospital care being unavoidable. This implies that the phases in the framework should not be taken as exclusive phases of one unilateral process. The phases are sequential in the sense that they need follow-up, but they also represent analytical dimensions in the caring process.

While close relatives, especially mothers, could take the leading role in phase one to three, the role of community-based health workers was more clearly defined as one of 'taking care of' or arranging care in the absence of relatives or partners. The community-based health worker's role in 'care-giving' is more or less restricted to scheduled home visits with the aim of carrying out specific activities, such as assessing the condition of the patients and supervise the client's taking of medication. It was only where primary care givers were not available during the day or where persons lived on their own that their role extended to other care-giving activities.

It also proved very difficult to separate care-receivers experience of care-giving from the responses of their caregivers. The interaction between caregivers and care receivers is a dynamic process of action, comprising a response to the care-giving by the care receiver, based on their experience of the care, followed by a response to that from the caregiver. Neither Tronto (1993) nor Niehof (2004) look into the issue of the caregivers' experience of the care process and the exchange of feedback between caregiver and care receiver. The experience of the caregiver is crucial as it may have implications for further arrangement of care. This is demonstrated by the case of Thembi (Case 4), where the care receiver became so agitated and aggressive that the primary caregiver, her mother, had to call the hospital to send an ambulance to fetch her daughter. In her study on elder care in the Netherlands, Luijkx (2001), who used Tronto's framework as well, also describes situations where care arrangements had to be changed because of changes in the care situation. Hence, at case-level the care process is not always a unilateral sequence of four exclusive phases, but phases may overlap and the whole process may have a cyclical structure that includes feedback mechanisms.

Through history, carers testified that caring is motivated by love and is experienced as a labour of love. However, sometimes the labour must continue even where the love falters or it is the love which remains, but due to circumstances or a lack of resources the care-giving required exceeds the capability and competence of the caregivers.

Note

Corrie du Preez works as an assistant professor at the University of Zululand, South Africa. The findings presented in this paper are part of the results of her PhD research, to be reported in full in her forthcoming PhD Thesis. Her e-mail address: cdupreez@pan.uzulu.ac.za. Anke Niehof is a full professor at Wageningen University, the Netherlands. Her e-mail address: anke.niehof@wur.nl.

The authors wish to acknowledge the support of the Netherlands Ministry of Foreign Affairs for their generous funding of the AWLAE Project, in the framework of which the research was carried out, and the support of the University of Zululand for granting Corrie du Preez study leave.

References

Akintola, O.
2004 *A gendered analysis of the burden of care on family and volunteer caregivers in Uganda and South Africa*. Durban: University of KwaZulu-Natal, Health Economics and HIV/AIDS Research Division.

Department of Health
2007 *Report National HIV and Syphilis prevalence survey South Africa 2006*. National Department of Health.

Donahue, J.
2006 Strengthening households and communities: The key to reducing the economic impacts of HIV/AIDS on children and families. *In*: G. Foster, C. Levine & J. Williamson, *A generation at risk: The global Impact of HIV/AIDS on orphans and vulnerable children*. Cambridge: Cambridge University Press, pp. 37-65**.**

Ferlander, S.
2007 The importance of different forms of social capital for health. *Acta Sociologica* 15 2): 115-28.

Finch, J. & J. Mason
1993 *Negotiating Family Responsibilities*. London and New York: Tavistock/Routledge.

Graham, H.
1983 Caring: A labour of love. *In*: J. Finch & D. Groves (eds), *A labour of love: Women, work and caring*. London: Routledge & Kegan Paul, pp. 13-30.

Hutchings, A. & G. Buijs
2005 Water and AIDS: Problems associated with home-based care of AIDS patients in a rural area of Northern KwaZulu-Natal, South Africa. *In*: A. Coles & T. Wallace (eds), *Gender, water and development*. Oxford: Berg Publishers, pp. 173-88.

Luijkx, K.G.
2001 *Zorg: Wie doet er wat aan – Een studie naar zorgarrangementen van ouderen*. Wageningen University: PhD thesis.

Niehof, A.
2002 The household production of care. *In*: C.A.A. Butijn et al. (eds), *Changes at the other end of the chain*. Maastricht: Shaker Publishing, pp. 179-89.
2004 A micro-ecological approach to home care for AIDS patients. *Medische Antropologie* 16 (2): 245-65.

Nombo, C.I.
2007 *When AIDS meets poverty: Implications for social capital in a village in Tanzania*. Wageningen: Wageningen Academic Publishers.
Rimmer, L.
1983 The economics of working and caring. *In*: J. Finch & D. Groves (eds), *A labour of love: Women, work and caring*. London: Routledge & Kegan Paul, pp. 131-47.
SCP
2003 *Over de hulp van en aan mantelzorgers*. Den Haag: Sociaal en Cultureel Planbureau.
Statistics South Africa
2001 *National Census of South Africa 2001*. Pretoria: South African Government Printers.
Tronto, J.C.
1993 *Moral boundaries: A political argument for an ethic of care*. New York, London: Routledge.
Uys, L. & S. Cameron
2003 *Home-based HIV/AIDS care*. Cape Town: Oxford University Press Southern Africa.
WHO
2005 *Treat 3 million by 2005, interim WHO clinical staging of HIV/AIDS and HIV/AIDS case definitions for surveillance*. Geneva: World Health Organisation.
2007 *TB and HIV country profile, South Africa*. Geneva: World Health Organisation.