Discussie

A micro-ecological approach to home care for AIDS patients

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In dit artikel wordt een conceptueel kader ontwikkeld om de relaties tussen de gezondheid van individuen enerzijds en de huishoudelijke productie van zorg en gezondheid anderzijds te onderzoeken. De ontwikkeling van een dergelijk kader, een 'micro-ecologische benadering van gezondheid', wordt gemotiveerd door het belang dat ik hecht aan het doorbreken van de scheidslijnen tussen de verschillende disciplines die zich met gezondheid van de mens bezighouden. In het eerste deel van het artikel worden de conceptuele lijnen uitgezet, gebruikmakend van bestaande theoretische benaderingen van huishoudelijke productie, zorg, en gezondheid. In het tweede deel van het artikel wordt de micro-ecologische benadering toegepast op de thuiszorg voor AIDS patiënten

[huishouden, gezondheid, zorg, HIV/AIDS, micro-ecologische benadering]

The micro environment and agency of the household: a theoretical statement

In the interdisciplinary field of household sciences, the household is seen as a unit of both consumption and production. The productive functions of households include providing for the primary needs of members, viz. livelihood and care. Households are 'care providers' (Gardiner 1997). With the decline of family farming, cottage industries and home-working in Europe, the image of the household as a productive unit faded, to give way to the image of the household as a unit of consumption. Household became increasingly synonymous with family in the sense of nuclear family. In the Western context the terms household and family are often used interchangeably. This shift in perspective obscures the view of the important productive functions of the household, even if it does not produce for the market. However, in the wake of population ageing, and the increasing care needs this entails, combined with the limits to the welfare state, households recapture their significance as care providers, also in (so-called) Western societies (Qureshi & Walker 1989, Luijkx 2001, Keasberry 2001, Niehof 2002).

The latter development is not only important for placing health needs and health care in a proper context but also paves the way for a comparative perspective on house-hold functions and processes. Chant (1997: 281) observes that writers on developing

countries tend to use the term household rather than family. She adds that in developing countries "the members of individual residential units are often embedded within strong networks of wider family and kin and it accordingly makes little sense to confine 'family' to small domestic groups. Alternatively, people in Northern countries often have less contact with relatives beyond the immediate household or their natal families and so the concept of family becomes prioritised in a household setting." The point of departure taken here is that "households represent to a large extent *the arena of everyday life* for a vast majority of the world's people" (Clay and Schwartzweller 1991: 1, my italics). Rudie (1995: 248) describes this 'arena of everyday life' as a "corresidential unit, usually family-based in some way, which takes care of resource management and primary needs of its members". Especially the last part of this description is important because health needs relate to primary needs and resources and resource management are needed to provide for them.

The vision of the household underlying this paper combines a systems approach with an actor or agency perspective. In a systems approach a system is considered an integrated whole working on inputs that are processed and managed (throughput), leading to outputs that are partly fed back into the system. It has boundaries and interfaces with other systems. The systems approach is the underlying paradigm of household models in the home economics and human ecology literature (Wingerd Bristor 1995). The household can be seen as a system insofar as it uses inputs (resources and assets) to produce outputs (care and well-being). The household organisation, including decision-making, management and developing and implementing strategies, can be seen as the system's throughput. There is feedback as well; outcomes affect the resource base of the household and subsequent household production. However, when looking at household organisation, also a certain agency can be attributed to the household. As collectives households, like all enduring groups, have emergent properties that exist above the individual level (Anderson et al. 1994). Households have agency, in the sense of 'reflexively monitored flows of conduct' that are subject to social differentiation and are influenced by the political economy (Carter 1995). While, to a certain extent, the household can thus be seen as one actor, intra-household inequities and dynamics play a role in household production as well, particularly those related to gender. Kabeer (1991) rightly points to the importance of the gender-based division of labour within the household economy, and the internal distribution of resources and welfare outcomes.

Focusing on the micro-level of the household does not imply seeing households as closed and static systems; household boundaries are permeable and household composition changes over time. Household members are part of social networks beyond their own household, and the household interfaces with other institutions. Households can be seen as agencies mediating between the individual and society. Within households social norms and cultural values are given concrete form. Households adapt to change ing external circumstances but by their internal dynamics they also generate change (Pennartz & Niehof 1999). This perspective is particularly important when studying health care practices and the norms underpinning them. In my opinion, for a sociological approach to health and health care one should start at the micro-level, viewing

micro-macro linkages from that perspective. In his plea for what he calls a micro reduction approach, Collins (1981: 93) puts it as follows: "Reduction produces an empirically stronger theory, on any level of analysis, by displaying the real-life situations and behaviours that make up its phenomena." Macro-level constraining or enabling factors, or opportunity structures (Pennartz & Niehof 1999), have to be analysed for the way they are experienced at the micro-level. As Collins notes, historical and structural patterns are empirically made up of long sequences and aggregates of micro-situations and interactions.

Health needs and care

Providing for the primary needs that Rudie refers to in her description of household is essential for preserving health. When a person's needs for food, nutrition, shelter and protection are not adequately met, his or her health is at risk. The literature on food insecurity and the consequences of malnutrition for children's physical and mental development testifies to the importance of meeting food needs both in the short and the long term (Kennedy & Peters 1992; Van Esterik 1995; Leemhuis 1998; Smith & Haddad 2000; Balatibat 2004).

However, availability of the necessary means to provide care at the household level offers no guarantee that the needs of all household members, particularly the most vulnerable ones, are adequately met. The internal arrangements within households that organise care work and assign care tasks should provide basic security and effectuate individual members' right to care. This household production of care requires resources, both tangible and intangible, as well as inputs in terms of time. It is underpinned by moral values and is part of what Cheal (1989) has called the 'moral economy of the household'.

The question of the quality of care provided within the micro context of the household requires further elaboration, and for this purpose I shall use Tronto's theoretical framework. Tronto (1993: 103) defines care as "a species activity that includes everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible." She stipulates that for an activity to be called care it has to include both care practices and the disposition (or intention) to care. She sees care as consisting of four interconnected phases:

- 1 Caring about: The identification of the need for care, which requires attentiveness.
- 2 Taking care of: Determining how to respond to the identified care need, requiring agency and responsibility.
- 3 *Care-giving*: Directly meeting the need for care by physical work and face-to-face contact, requiring *competence* of the caregiver.
- 4 *Care-receiving*: Assessing the adequacy of care, calling for *responsiveness* on the part of the care receiver.

To the four requirements of good care – attentiveness, responsibility, competence, and responsiveness – Tronto adds a fifth one, namely integrity; implying that the four

phases should be linked into a well-integrated care process. Integrity is lacking when, for example, care needs are identified but no one is taking responsibility or when those who are taking responsibility subsequently delegate the problem to caregivers without bothering to check whether these are adequately equipped for their task.

All four phases of care and five requirements of good care play a role in the household production of care. As much as possible care-giving is done within the household. However, when the care need of a household member exceeds the capability of the household to meet it, somebody in the household has to take responsibility to find an alternative solution. There are basically two types of circumstances in which this may occur. The first is that the household lacks the competence to give adequate care, in which case the help of medical professionals or medical institutions has to be sought. The second is that there is a general lack of the necessary resources and capabilities. As discussed above, the household production of care requires the use and management of resources, including time. In this case as well, external help might be needed, perhaps to the extent that external agencies have to identify the care needs and take responsibility to do something about them. In the latter case we are talking about a household in distress, unable to meet even the minimum standards of care provision, in which the health of individual household members is at risk. Such households may be very resource-poor, with vulnerable livelihoods, or stricken by disaster, or just unable to cope with the crisis they are faced with. Tronto's framework provides the criteria for assessing the adequacy of care produced by households and the entry points for meaningful assistance by external agencies, medical or non-medical.

The concept of the 'therapy managing group', coined by Janzen (1978) for Zaire, fits particularly well in the second phase of Tronto's framework (taking care of). Janzen (1978: 4) describes it as follows. "A therapy managing group comes into being whenever an individual or set of individuals becomes ill or is confronted with overwhelming problems. Various maternal or paternal kinsmen, and occasionally their friends or associates, rally for the purpose of sifting information, lending moral support, making decisions, and arranging details of therapeutic consultation. The therapy managing group thus exercises a brokerage function between the sufferer and the specialist."

The contours of the micro-ecological approach to health and health care are now drawn. Before assessing the overlap with similar frameworks, two more elements that are part of the approach must be mentioned here. The first is gender. As has been convincingly demonstrated in the literature (Fisher and Tronto 1990, Tronto 1993, Taylor et al. 1996), care is gendered. In many societies actual care-giving is dominated by women, while 'taking care of' is usually done by persons in a position of authority with control over resources, in many societies predominantly men. Whatever the precise division of tasks and responsibilities, nowhere is care a gender-neutral activity. This means that the micro-ecological approach has to be a gender-sensitive one that takes into account prevailing gender roles and values, to relate these to health and care.

The second issue is that of the circular mode of care production. Tronto's framework includes the element of feedback (phase four). However, also in a more general sense the 'outputs' of domestic production have an impact – positive or negative – on

the subsequent use and allocation of the resources needed for adequate care. An example of negative feedback is provided by a research project in Sri Lanka (Hoogvorst 2003). In the study area, poverty-fuelled alcohol abuse by husbands leads to the depletion of household resources and their wives' loss of social esteem and social relations, affecting the care-giving ability of the household as a whole and of the wife in particular.

Alternative frameworks

The Household Production of Health (HHPH)-framework

In 1994 a special issue of the journal *Social Science and Medicine* was devoted to an approach to health care called the household production of health (HHPH). In formulating their position, the authors (Berman et al. 1994) observe a gap between the multifaceted nature of sociological or anthropological studies of human behaviour and the focussed character of disease control programs. To bridge it they propose an approach aimed at understanding the "process by which inputs to households become outputs in terms of health improvement" (Berman et al. 1994: 206).

In relation to public health campaigns and programs, the HHPH framework emphasises that programs should focus on health enhancement and maintenance, rather than on the prevalence of specific diseases. In the framework, the household is seen as the locus of health production, without implying that households control all resources needed for health maintenance. The institutional environment of the household includes formal health services. These are seen as external resources which households can use to maintain and promote health. To which I would add that the extent to which households can use these external resources will differ according to a) the value they attach to them and b) the household's capabilities and entitlements to access them. Berman et al. distinguish the following domains of intra-household health behaviours: infant and child-feeding practices; child care; home diagnosis and treatment and utilisation of home-based services; home hygiene and sanitation behaviour; and ante-natal and post-partum care of women. In addition, they subsume a wide range of health- and treatment-seeking behaviours under household production of health, such as the use of external health services, financial investments in health, like home improvements and purchasing health-related capital goods.

In its emphasis on households as a context for health-producing behaviours, for which inputs (resources) are needed, the HHPH framework is similar to our approach. However, there are some gaps as well as matters that are not entirely clear in the HHPH framework and need to be remedied.

First, as an external resource, the institutional environment relevant for health production should not be limited to formal health services. It has to include the informal health sector, like the services of indigenous healers and providers of indigenous medicine. If one sees the household as a 'soft' system that interfaces with other systems and is embedded in a certain environment, the argument may be extended even further. A

household's external resources are located in its natural environment, its material and man-made environment, and its socio-cultural and institutional environment. The household's ability to produce health will depend on the availability of these external resources as well as on the capability of households to access them. For example, the availability of fresh water in the natural environment constitutes an important external resource. When this is unavailable, the conditions for producing health, i.e. safe water, hygiene and sanitation, can hardly (or not at all) be met, which will result in specific morbidity patterns.

The second issue concerns the word *to* in the description of the HHPH approach cited above. By seeing outputs in terms of health primarily as processed inputs *to* households, the agency of the household in generating and managing resources itself is glossed over. The household is treated again as a black box; something is put in and something comes out, but what happens inside remains invisible. Berman et al. list the types of activities that are part of the household production of health, but we are left without a clue as to how this production takes place. Inputs are not just there but have to be acquired. Resources have to be generated or accessed, allocated, used and managed. The way this is done will determine the outputs, also those concerning health. The HHPH approach is not specific enough about a crucial component: the P of production.

The last point I would like to make concerning the HHPH approach, is that it does not distinguish between intended health behaviour and behaviour having no health purposes, but leading to certain health outcomes. No use is made of the concepts of etic and emic that played such an important part in the theoretical development of medical anthropology, and led to the useful distinction between illness and disease. By 'emic' we mean classifications that refer to a "logico-empirical system whose phenomenal distinctions [...] are built up out of contrasts and discriminations, significant, meaningful, real, accurate, or in some other fashion regarded as appropriate by the actors themselves" (Harris 1968: 571). Such an emic classification can be contrasted to an 'etic' one, defined by Harris (1968: 575) as depending upon "phenomenal distinctions judged appropriate by the community of scientific observers". In short, disease is an etic category and illness an emic one. In spite of the considerable discussion in the literature about the relevance of the emic-etic distinction (e.g. Feleppa 1986, Headland et al. 1990), we think that it is relevant and useful for the approach proposed here. Because Tronto sees care as practice and as disposition, calling behaviour 'care' only when it is intended as such - whether or not medical professionals (etic perspective) see it as care, her model also contains an emic perspective. When the emic-etic distinction is applied to the household production of health, the following matrix emerges.

Table 1	Classification of health care practices in the household production of health	
	(HHPH) according to the emic and etic perspectives	

Etic perspective	Emic perspective	
	No health care intentions	Health care intentions
No measurable health effects	(1) Not a relevant category	(2) HHPH practices intended as health care but not yielding measurable health effects
Measurable health effects (positive or negative)	(3) HHPH practices not intended as health care but yielding measurable health effects	(4) HHPH practices intended as health care and yielding measurable health effects

'Measurable health effects' can include both positive and negative ones. An example of a practice intended as health care but, actually, yielding measurable negative health effects (fourth category) is what I could observe myself during my fieldwork in Madura, Indonesia. The practice I am referring to is the following. Persons clearly suffering from tuberculosis would consult an indigenous healer, who would soak in a glass of water a piece of paper inscribed with a text from the Koran, give the glass to the client to drink, and promise recovery from the disease. Because tuberculosis is a deadly disease when not treated properly, and a highly contagious one, and because the treatment does not address its (etic) causes, this practice obviously has measurable negative health effects. It fits within the HHPH framework because the decision to go to the healer is not an individual action. It is taken within the household and the means for paying the healer are provided and allocated by the household. As pointed out above, traditional healers are part of the institutional environment of the household, which includes not only health services in the formal sector but also those within the so-called informal sector.

A critical ecological model for medical anthropology (CEMMA)

In developing the critical-ecological-medical-anthropology framework Young (2002) combines ecological approaches to health with critical medical anthropology. She then uses the resulting framework of critical ecological medical anthropology to analyse the problem of anaemia during pregnancy in Pemba (Zanzibar).

Young sees the strength of medical ecology in its comprehensive treatment of biotic, non-biotic and social environments, making it possible to relate the biological, the social and the cultural in the analysis. However, ecological anthropologists are often reproached for being too materialistic and for failing to give proper consideration to the role of social relations and cultural factors. They tend to focus on people's adaptation to the physical ecosystem, treating the latter as given, rather than considering the role of social, cultural, and political factors in shaping people's responses and shaping the environment. The opposite is the case with critical medical anthropology, because

"critical medical anthropologists prefer to examine the social and historical forces of the political economy as dominant determinants of health and disease" (Young 2002: 335). The latter are the very factors ecological anthropology is accused of as neglecting, while critical medical anthropologists are accused of paying scant attention to the biological environment and physical factors.

Young's deconstruction of the concept of *adaptation* is particularly relevant for our purposes. While warning against the risk of using the concept in a tautological manner (illness as a failure to adapt) or in a functionalistic way (adaptation as a way to preserve the balance of the system), she wants to retain it. She sees adaptation as the ability to respond to or to seize opportunities, and this ability as being circumscribed by the resources available to the individual or group. Included in her conceptualisation of adaptation is 'cognitive adaptation', meaning that we can change the way we think about things, such as health, in order to put ourselves at ease. When phrased in this way, cognitive adaptation bears close resemblance to what sociologists have always referred to as solving the problem of cognitive dissonance. If you cannot change an unwanted situation, you can adjust your description or perception of it to bring it more in line with the desired situation.

On the basis of the theoretical discussions summarised above, Young presents her critical ecological model for medical anthropology (CEMMA). Its interesting characteristics are a broader definition of the environment to include historical, political, economic, biological and symbolic forces, and an expanded definition of adaptation to include the notions of tactical adaptations and cognitive adaptation. The model is visualised in a figure (Young 2002: 342) in which five boxes are placed in a field that bears the text 'ideational setting'. The mental and physical needs of individuals are in the central box. It is linked to four other boxes that contain the micro-level social setting (the household), the meso- and macro-level social setting (history, economics, and politics), the physical setting, and medical technology. When the model is applied to the case of anaemia during pregnancy, the boxes and the field are filled in with specifications ('ethnographic flesh') that fill almost an entire page. The connections between the boxes and between the boxes and the field are formed by adaptations.

Young's framework has a number of attractive features. It comprises the material and the immaterial environment, both tangible and intangible factors that influence, or even determine, people's health, both directly and indirectly. In the way adaptation is conceptualised the constraining or facilitating role of resources is acknowledged. Furthermore, the notion of cognitive adaptation can be related to the emic-etic distinction. However, while acknowledging these plusses, I do object to the central position of the individual's mental and physical needs in the model, because – at the end of the day – providing for those needs is not done individually but in the context of the household. The emphasis should be not on the needs themselves but on the manner in which they are met. The provision for basic mental and physical needs on a daily basis requires allocation and management of household resources, which is why the household is the fitting level of analysis. The authors of an article on household strategies to cope with the economic costs of illness in Burkina Faso conclude that "the household, rather than the individual ill person, was the appropriate unit of analysis" (Sauerborn et al. 2000:

291). This is because households and not individuals bear the costs. They affect the household resource base and are allocated by household decision-making.

In the next section we will formulate the micro-ecological approach as an alternative framework by making a synthesis of the contours outlined in the first section and the building blocks provided by the frameworks of HHPH and CEMMA.

Summarising the micro-ecological approach to health (MEAH)

The approach presented here will be referred to as the micro-ecological approach to health, abbreviated as MEAH. Its key elements are the following:

- (i) As in the HHPH approach, for the production of health the household is taken as the level of analysis. Household characteristics, such as size, composition, dependency ratio, phase in the household life course, and household headship, are assumed to affect the capability of households to produce health and provide adequate care.
- (ii) Within households resources are allocated and managed to provide for basic needs, including the mental and physical care needs of its members. Likewise, assets are saved, kept, enhanced, or – if unavoidable – cashed-in and depleted, to provide for basic needs, including care needs. The way this is done can be more or less sustainable or strategic, reflecting the degree of vulnerability of the household's livelihood system.
- (iii) Vulnerable households have a structural lack of resources, assets and capabilities. When confronted with a crisis or a shock such households can only try to cope, using the few options they have. Coping is short-term responsive behaviour directed at day-to-day survival, because the actors are incapable of structurally improving the situation.
- (iv) The household is embedded in an environment that comprises physical components, institutional structures and cultural and normative frameworks. Both formal and informal health care institutions are part of the institutional environment of households. Such institutions constitute an environmental resource that households will use if they perceive them as valuable and also have the means to access them.
- (v) The institutional structures also include kinship networks and other social networks as well as institutionalised inter-household support relationships. These have a two-fold significance. First, they represent a resource or asset (in the sense of claims) that can be of immediate support, such as labour and support. Second, they have an intermediary function by providing access to other resources and assets. The institutional structures can also be a liability instead of an asset, when they constrain households and individuals by making excessive claims on them or by draining their resources. This is a matter of perspective as well. To needy family members the kinship network is a resource, but to the households appealed to for help the relatives becomes a burden.
- (vi) The adequacy of care is judged by the extent to which care needs are properly identified, are taken responsibility for, are addressed by competent care-giving

practices, are positively appreciated by the person to whom care is given, and are communicated and integrated. At the same time, the adequacy of care is to be judged 'objectively' by assessing the measurable health effects.

- (vii) Care is not just disposition or intention to care or practice but a combination of both. Care can yield measurable health effects or not, which can be positive or negative.
- (viii) The normative frameworks that households are embedded in and interface with, are part of religious, ideological, and cultural structures that largely determine the legitimacy of care needs and claims and the social acceptability and emic efficacy of care practices.
- (ix) Gender plays an important role in all these processes. The phases in the process of care are gendered, as are access to and control of the resources and assets required.

To sum up: MEAH stands for a gendered approach to health and health care that looks at the adequacy of the way and the extent to which care needs of individuals are met by the disposal, allocation and management of internal and external resources of the household they live in.

AIDS and society

The AIDS pandemic is much more than a series of personal and family tragedies. AIDS' deaths have depleted the workforce, lowered life expectancies, and are likely to shred the already torn social fabric of numerous countries (Schoepf 2001). Against this background I intend to show how the micro-ecological approach to health can be applied to home care for AIDS patients. This requires some preliminary reflections on AIDS as illness.

The disastrous ramifications of the AIDS pandemic are becoming increasingly felt, visible, and – though according to some authors rather belatedly – acknowledged. Schoepf (2001: 351) says the following on WHO's health-for-all objectives: "With public health systems a shambles, even in countries with little HIV/AIDS, however, the goal of 'Health for All by the Year 2000', agreed upon by world leaders at Alma Ata in 1978, is a farce today." In their book, Barnett and Whiteside (2002) comment sharply on the absence of AIDS statistics and the lack of a systematic inclusion of AIDS effects on development in World Bank and UNDP reports. To go thoroughly into the reasons for this neglect is beyond the scope of this article. However, some aspects need to be highlighted here. The first is the nature of the pandemic, described by Barnett in a paper as a slowly moving disaster. "The AIDS pandemic differs from other disaster events in two ways. It is slow-acting and almost surreptitious with no clear trigger mechanisms. Thus the incremental rate of increased mortality associated with AIDS may mean that communities are not aware of the extent and novelty of the crisis until well into the pandemic" (Barnett 1992: 9).

The second aspect is that of the insufficiency of biomedical models alone to explain and describe the pandemic in combination with the moral overtones of alternative social and cultural explanations. Regarding the impact of the pandemic in Sub-Saharan Africa, sweeping statements have been made about 'African sexuality'. This can lead to misplaced attitudes of moral superiority, resembling the way homosexuals suffering from AIDS were stigmatised in the United States and Europe (and in some corners still are). The fact that the AIDS discussion is fraught with moral and cultural sensitivities might be a reason to avoid or ignore it. Still, sexual behaviour is a key variable in the spread of HIV/AIDS, which is why Caldwell et al. (1989) in their early paper on the social context of AIDS in Sub-Saharan Africa make a plea for the analysis of sexual networking practices. However, this behaviour takes place in a certain context or environment. Barnett and Whiteside (2002: 81) see risky behaviour as "a characteristic of the environment rather than of the individuals or the individual practices".

A profile of AIDS as illness has to include a brief discussion of its temporal ramifications. Barnett and Whiteside (2002) wonder what AIDS will do to people's lives over many years and decades. In their article on AIDS-orphans Deininger et al. (2003: 1217) note that "even if the immediate impact of AIDS on mortality is in decline, the legacy of longer-term negative welfare impacts will constitute a formidable challenge for the foreseeable future." They cite Uganda as a case, where a dramatic increase of AIDS-orphaned foster children and households hosting them can be observed. This phenomenon belongs to the fourth of the long-wave events that Barnett and Whiteside associate with AIDS. The four waves are that of HIV infection, spread of tuberculosis because it is the most common opportunistic infection, spread of AIDS illness and death, and, finally, the wave of impact, which includes household poverty and orphaning (Barnett and Whiteside 2002: 23).

At the micro-level of households and individuals HIV/AIDS also follows a distinctive, non-reversible time path, mirroring that of the macro-level sequences. At the individual level, once an individual is infected, there is a time lapse of several years before the illness becomes manifest. This period of clinical latency seems to last for about seven years. The first sign of AIDS is the affliction by opportunistic diseases. Then, the symptoms become aggravated until the patient dies. Barnett and Whiteside (2003) cite a study in which it was found that the time from falling ill to death was shorter for untreated patients in Uganda than for patients in rich countries, but that the period from infection to illness did not seem to differ. At the level of the household the impact of the disease becomes gradually visible. In a case pictured by Barnett and Blaikie (1992: 89) a relatively prosperous household in the Rakai district in Uganda is gradually reduced to destitution in eight years. The adults die and the surviving children try to cope by growing food crops for their own consumption and selling their labour to neighbours.

Barnett and Whiteside (2003) point out two household-level phenomena induced by AIDS. The first one is the clustering of impacts within and between households that is a consequence of intra-household infection and households sharing the same risky environment. In such an environment, relations of proximity and neighbourhood, sexual relationships, kinship relations and other social relations within and between households make them share impacts, whether they want to or not. In a certain area, AIDS impacts are not just randomly distributed over persons and households, they are clustered. The second phenomenon is the total collapse of households. Households un-

able to cope because they sold all their assets have no social capital left to fall back on and are part of a severely afflicted cluster of households, collapse and disappear. Traditional household surveys are inadequate tools for detecting these vanished households, which results in a positively biased picture of the ability of households to cope.

Applying the MEAH framework to home care for AIDS patients

A case

Bos et al. (1996) documented the following case, placed in Zimbabwe:

Sam (42) is married to Liza (38). They have six children. The eldest (15) is at school in Bulawayo. The youngest is Pinkie, at the time of the first visit by the researchers, a baby of three months old. Up till October 1994, the household had a solid resource base. Sam worked in a factory in Bulawayo. At home in the rural area, Liza cultivates maize and beans. They have ten cows. The homestead comprises two buildings.

Sam began to feel ill in October 1994. At first he tried to keep working, with Liza visiting him as often as possible to provide care. This arrangement lasted only for a few months. Sam becomes too ill to work at all and returns home, bringing three months salary from his employer. The employer also arranges for a visit to a doctor and pays for the medicines. At the Bulawayo hospital Sam is diagnosed as sero-positive, indicated by the 'NS+' on his card (NS standing for New Serology, euphemism). Sam knows he has AIDS but does not acknowledge it. He claims Liza has bewitched him and pays frequent visits to the traditional healer.

Soon his condition begins to deteriorate. He is bed-ridden, emaciated, and is plagued by diarrhoea, tuberculosis, and ulcers. Because the homestead lacks a toilet, Sam has to use that of the neighbours. Liza has to support him when he goes there, because he is too weak to go by himself. Sam's parents have persuaded him to hand over his savings to them. This means Liza no longer has the money for medical costs, including the visits to the traditional healer, and for the children's school fees. Sam's parents share their son's view that his wife bewitches him. The accusations make Liza feel depressed and angry, but there is nothing she can do about it.

When Sam dies, baby Pinkie soon follows. Liza, who is feeling increasingly ill herself, asks her mother to come over and help. Meanwhile, unpaid bills, including those of the funeral, pile up. Then, Liza decides to go back to her parental home, about 60 kilometres away. She is only allowed to bring the youngest children with her. The elder ones have to stay behind at the homestead of their deceased father's family. At the home of Liza's parents, her daughter has to leave school because she has to help her grandmother run the household, Liza being too ill for that.

The case presents a depressing picture of the burden on a caregiver looking after a household member suffering from AIDS in a situation of increasing vulnerability. It shows how assets are depleted and resources have to be re-allocated. The clustering effect at household level is clearly visible; the household of Sam and Liza comprises

three persons (including the baby) who are – in varying degrees – suffering from the disease. Accusations of witchcraft express the ruptures in relationships once based on trust and support. Kinship becomes a divisive force instead of a form of social capital. There is no longer a functioning 'therapy management group'.

Phases and adequacy of care

Returning to Tronto's framework (see above) and using it to judge the adequacy of home care for AIDS patients, we can see that the first phase, that of *caring about*, is already problematic. Bos et al. (1996) describe the uneasy silence surrounding AIDS, at least at that time, in rural Zimbabwe. Such a situation inspires fear, ambiguity and denial, rather than attentiveness and responsibility (Radstake 2000). Euphemistic names and labels are devised, even by the hospital (allegedly to avoid stigmatising patients). In their article, they report on the existence of volunteer groups who visit patients at home. Though religiously inspired and boosting morale by organising praying sessions at afflicted homes, they are not insensitive to the practical problems of home care for AIDS patients. They report back to the hospital and try to provide practical support to the afflicted families whenever possible. They are attentive and take responsibility, but their means and capabilities are severely limited, however important they are for identifying critical cases.

Liza was attentive. She went to town to care for her sick husband and, later, cared for him at home. She had picked up the signs and took her responsibility (phase two). The same goes for Sam's employer who did what he could within the limited means at his disposal and given the boundaries of his responsibility as an employer. Liza's caregiving (phase three) is severely constrained by lack of means. The main resource is her own labour, but because of her failing health this resource is also under stress. Much to Liza's distress, Sam frequently invokes the help of a traditional healer, thereby depleting whatever is left of their dwindling savings. In the matrix (Table 1) this behaviour can be placed in box 2 (HHPH practices intended as health care but not yielding measurable health effects). In the patrilineal setting Liza lives in, the household's assets belong to the husband's family, and, at some point, she is denied access to them. This undermines Liza's agency and capabilities as a caregiver, not only for Sam but also for the family as a whole, including baby Pinkie. In Tronto's framework competence is an important requirement for adequate care-giving. But, although Liza might not be a sufficiently competent caregiver, she is the only one Sam has. Medical competence is located outside the household. The medical institutions in the area neither have the resources to do their care work properly, nor do Sam and Liza have the means to avail themselves of competent medical assistance.

The fourth phase of Tronto's framework is that of receiving care, which requires responsiveness on the part of the recipient. This too, is problematic in the case of Sam and Liza, and, presumably in similar cases as well (cf. Radstake 2000).

In the case outlined above, the care provided cannot be called adequate. It does not yield measurable positive health effects. In the case of AIDS we cannot expect the patient to be cured, but it is possible to do more about the opportunistic infections and

make the patient feel more comfortable, mitigating the effects of the disease. Even if Liza is aware of this, there is not much she can do about it. In the institutional context there is denial rather than attentiveness and support. The hospital does not or cannot take its responsibility, being deprived of the necessary means and governmental support. The patrilineal kingroup leaves the couple to their own devices, while trying to save whatever assets are left. For competent and adequate care-giving, the primary caregiver is ill-equipped. The household lacks the resources and facilities to ease the caregiver's work. The recipient lacks positive responsiveness. The care process is not well integrated. While Liza tries desperately to give care in spite of her own ill health, Sam – equally desperate – seeks the help of a traditional healer, thereby further depleting household resources needed for him but also for the other members of the family. Sam and Liza differ in the way they perceive the illness and in their belief in the efficacy of traditional medicine, at least for this illness. The conclusion has to be that quality of care in cases like that of Sam and Liza leaves much to be desired. It is a situation of a household in distress, unable to meet even the minimum standards of care provision, in which the health of individual household members is at risk. This works in two ways. First, the household's resource base deteriorates to the extent that, increasingly, basic needs for all household members cannot be sufficiently met. Second, there is a lack of additional resources needed for adequate caring for ill household members. Clearly, in such a case the external relationships of the household concerned and its access to resources in the environment become crucial.

In a study on home care for people living with AIDS in Ghana (Radstake 2000) similar patterns as those displayed in the case of Sam and Liza can be discerned. The care for AIDS patients is hampered by poverty (lack of material resources) and by secrecy and ambiguity. Additionally, Radstake (2000: 50) points to the phenomenon that patients and care givers alike perceive care as contributing to cure, which goes against prevalent medical opinion. One might see this as an example of Young's cognitive adaptation.

The societal context and community support

In outlining the MEAH framework it was said that households are embedded in an environment with which they interface. In the case of HIV/AIDS the political economy of AIDS (Lugalla 2001) exerts a profound influence on the quality of care for AIDS patients because it is a determining factor in the availability of resources and support at community and household level. The 'moral economy' of a household (Cheal 1989) always functions within a given political economy.

Gendered normative and cultural frameworks further impact on the agency of the predominantly female caregivers. In a patrilineal rural society where virilocal residence prevails, women's capability to provide care is constrained by their lack of entitlements. In the end, women caregivers not only lose their husband but, in addition, often have no other choice than to go back to their own family and leave their children behind. But also in non-patrilineal societies women may lack the entitlements and resources to carry out their culturally and socially assigned role as caregivers (Taylor et

al. 1996). For most people in poor societies, home care for AIDS patients is the only option, since they cannot afford hospital fees, even if hospitals were sufficiently equipped to deal with the problem. This home care becomes the duty of women. In the case of the AIDS pandemic in Sub-Saharan Africa, it seems as though the nature of the political economy and prevailing cultural and social systems conspire to place an unbearable burden on female caregivers.

The problematic situation sketched above has given rise to initiatives aimed at community-based care for AIDS patients. The volunteer groups in the case of Sam and Liza were already mentioned. It has to be noted that these groups consist mainly of women and find it difficult to enlist the participation of men (Bos et al. 1996). For several reasons, however, one must not expect too much from community-based care towards providing sustainable solutions, even though it may be affordable in economic terms (Msobi and Msumi 2000). It is important to look critically at the concept of community that inspires such initiatives. Neither the household nor the community is a unified actor. Community structures may be based on values of solidarity and reciprocity, but there are inequalities as well. Furthermore, the same pressure that the AIDS pandemic exerts on the household's resource-base and capabilities, it also places on the community. As Taylor et al. (1996: 55) note: "Demand for valuable resources will also increase as members of a kinship group or community are affected by the same event. In turn this may precipitate the breakdown of the traditional household and community reciprocal relations on which Africa has relied for so long." AIDS depletes the potential for therapy managing groups (Janzen 1978). Schoepf (2001) observes that the AIDS pandemic has caused anthropologists to argue against the reification of the ideas of community, clan, and extended family. Instead, they are now more alert to the social, economic, and religious differences that divide local actors.

While community-based care for AIDS patients may be the only recourse and resource left to overburdened, desperate, and – often – ill caregivers at home, it can only function when the community itself is not deprived of nearly all of its material and social resources. The social capital embodied by communities is not infinite, and can be eroded and depleted in a situation of scarce resources where social relationships are stretched to breaking point and trust degenerates into accusations of witchcraft. The effects on the community of the clustering of the illness (Barnett and Whiteside 2002), both within and between households, should be kept in mind as well. Initiatives of community-based care for AIDS patients that are based on a naïve conception of community, will fail.

Limits to coping

Recently, several authors have questioned the application of the concept of coping. If a household slowly recovers from the strain on its resources caused by a household member being ill and eventually dying from AIDS, one might say that it was able to cope. However, "coping might turn out to be another way of saying 'desperate poverty, social exclusion and marginalisation" (Barnett and Whiteside 2002: 190). Rugalema (1999) also claims that the concept of coping tends to mask poverty and desperation,

calling it an ideological notion. Loevinsohn and Gillespie (2003: 15) talk about the 'illusion of coping' and call the word 'coping' a misnomer. In the case of Sam and Liza described above, Liza evidently could *not* cope. In the end, she lost nearly all she had and could not keep her own family together. Whether or not a household was able to cope can only be determined in retrospect. Households that cannot cope dissolve and become invisible. They are the vanished households that Barnett and Whiteside (2002) talk about. Hence, the picture of households' ability to cope becomes positively biased.

In their article on household strategies to cope with the economic costs of illness, Sauerborn et al. (1996) point to the incremental nature of coping. While coping can be 'successful' in the short run, it often reduces the household's ability to cope with future adverse events. As noted above, the household production of health and care proceeds in a cyclical manner. In many cases, the resources needed for the provision of care, cannot be regenerated and are lost as inputs for future household production. Assets may have been cashed-in, which affects the ability of the household to acquire new ones. Another point made by Sauerborn et al. (1996) is that poor households have less access to inter-household support networks (a form of social capital) than households that are better off, while the former need it more desperately. In their study "both kin and community support (loans, gifts) were generally not available to poor households" (Sauerborn et al. 1996: 298). This confirms the claim by Barnett and Whiteside that coping may be another word for social exclusion and marginalisation.

The conclusion has to be that the concept of coping should be applied cautiously. Coping has a price tag. When people (try to) cope they do so at the expense of their resources and assets, including the claims they have to the support of others, which further increases their vulnerability. If they cannot cope, they disappear from sight. For these reasons, Loevinsohn and Gillespie (2003) prefer the word 'responding' to that of 'coping'.

Conclusion

In this article a micro-ecological approach to health (MEAH) was developed and applied to the subject of home care for AIDS patients in Sub-Saharan Africa. The application of the micro-ecological approach to the subject of home care for AIDS-patients reveals several crucial issues, which will be briefly discussed.

The predominantly female caregivers are severely constrained in their care-giving. They lack the necessary resources, are often ill themselves, and are insufficiently supported by the relevant institutions in their environment. When applying Tronto's criteria for good care, all phases in the care process seem to be flawed. On the part of the caregiver there is the intention to provide care, but competence and the necessary means are lacking. The problems posed by AIDS exceed the capability of the household. Even if responsibility is taken there, it is too heavy a burden. Therapy managing groups are no longer emerging or fall apart. When applying the micro-ecological approach this becomes painfully clear. Poor households trapped in a situation of having to care for one or more persons suffering from AIDS can hardly do more than try to

cope. Their efforts at coping are often futile, resulting in the dissolution of the house-hold.

The emic and etic descriptions of AIDS are phrased in widely differing terms. The emic perspective is the one most difficult to elicit. AIDS as illness represents a complex of complaints and symptoms that the people do not call AIDS. AIDS is hushed-up rather than talked about. In the case of Sam and Liza discussed above, the patient (Sam) does not want to know he has AIDS and constructs an alternative explanation for his afflictions (witchcraft), while the caregiver (Liza) knows but keeps silent. The patient seeks recourse to a traditional healer, while the caregiver worries about how to pay for these expenses. We categorised Sam's visits to the traditional healer as 'intended as health care but not yielding measurable health effects' (see Table 1). This is, of course, debatable. To Sam these visits might constitute proper care and have positive psychological effects that may help him endure his suffering, amounting to what Young calls 'cognitive adaptation'. For a proper emic analysis of Sam's behaviour, Sam himself would have to be interviewed, which was not done. To Liza the costs of these visits are expenses that threaten the already fragile resource-base of the household, impede her capability to provide care, and, in this way, have a negative health effect.

The role of traditional healers in treating persons suffering from AIDS is a problematic issue. Schoepf (2001: 351) notes that it is problematic for anthropologists as well: "The role of healers in hastening the death of lingering AIDS sufferers is spoken of by anthropologists *en coulisse* (offstage) but is not reported in the literature." Of course one may wonder, as Schoepf does, whether persons like Sam would go to a healer if the social conditions were different and the household would have had access to good medicine and competent medical care. In this respect as well, we are reminded of the fact that the capability of households to provide care is affected by the political economy in which they are embedded.

The approach outlined in this article is, because of its household focus, poorly applicable to persons not living in households. It is applicable to one-person households, the percentage of which is steadily increasing in Western societies like the Netherlands (Van Nimwegen & Esveldt 2003). However, for such households the limits of their care-taking and care-giving potential are quickly reached and it is essential for them to be embedded in formal support structures and informal support networks that can play a role in all four phases of care. The MEAH framework is less applicable to individuals living alone in marginal conditions or in unstable groups, such as street children. The absence of a household context makes them vulnerable. Others will have to be alert to their care needs, will have to take responsibility and provide care-giving when needed. Lugalla & Kibassa (2002) point to the importance of networking by street children as a way of creating a fall-back position that – to a certain extent – can function as a health management group. Obviously, the lack of resources and capabilities will severely constrain the production of health and the adequacy of care.

The MEAH framework proposed in this article provides a tool for identifying care needs of individuals and households and assessing the constraints in meeting them. In this article the framework has been applied to home care for AIDS patients, but it can likewise be applied to children's nutrition, elderly care, chronically ill patients, and so

on. Using it will always entail looking into household resources and capabilities as well as mapping the social and institutional environment of the households concerned.

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Note

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Care, power and macro-level/micro-level analysis

Some suggestions for linking Niehof's "Micro-Ecological Approach" with other compatible models

Gretel H. Pelto

Anke Niehof has contributed a welcome, lively and thoughtful analysis to the on-going discussion of conceptual models that can be used to link individual health and sociocultural conditions. The significance of the household as the essential lynchpin between health and society still fails to receive central attention, either from scientists and scholars or from program planners and implementers. The lack of serious attention to household dynamics and conditions is difficult to explain. The inclusion of household demographic and economic characteristics in epidemiological, sociological and econometric studies is evidence of tacit recognition, but these are typically treated as "control" variables, rather than being seen as central to understanding social-health relationships. Implicit in Niehof's paper is the idea that at least part of the neglect of the household, as a fundamental locus or unit of analysis, is due to a lack of strong conceptual models that can serve to guide both research and program activities.

Niehof's skillful introduction of "care" into the conceptual model for health-society linkages is an important contribution. In nutrition there is a growing literature on the role of care for understanding the determinants of malnutrition in children in developing countries. UNICEF (1990) published and widely disseminated "The UNICEF Conceptual Framework for Determinants of Nutritional Status" in which the underlying causes of childhood malnutrition were categorized as "insufficient household food security," "inadequate health services and unhealthy environments," and "inadequate maternal and child care." These, in turn, are seen as the result of basic causes, which rest on fundamental economic, social and political structures. The framework is now so widely cited and accepted in nutrition that it has taken on iconic status. More recent work on care and caregiving has ranged from efforts to synthesize the methodological and theoretical support for the concept (Engle et al. 1996), to examination of its role in young child feeding (Pelto et al. 2003), to empirical studies (Leroy 2005). To reach out to the public health nutrition audience, it will be useful if Niehof explicitly links her model to the nutrition and care framework so that the value of the household focus can be more directed highlighted for that audience.

Niehof's model draws attention to the range of societal-household-individual dynamics that can be subsumed under the general heading of 'macro-level/micro-level linkages.' In the present version of her model these are implicit, but they are not actu-