Fragility, fluidity, and resilience: caregiving configurations three decades into AIDS

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ABSTRACT

HIV and AIDS have impacted on social relations in many ways, eroding personal networks, contributing to household poverty, and rupturing intimate relations. With the continuing transmission of HIV particularly in resource-poor settings, families and others must find new ways to care for those who are living with HIV, for those who are ill and need increased levels of personal and medical care, and for orphaned children. These needs occur concurrently with changes in family structure, as a direct result of HIV-related deaths but also due to industrialization, urbanization, and labor migration. In this special issue, the contributing authors draw on ethnographies from South Africa, Swaziland, Lesotho, Zambia, and -- by way of contrast -- China, to illustrate how people find new ways of constituting families, or of providing alternatives to families, in order to provide care and support to people infected with and affected by HIV.

For nearly half a century, scholars have recognized the various ways that families are constituted – ways that go beyond rigid arrangements and grand theories about marriage and reproduction that characterized the structural approach to kinship prior to the feminist turn in the 1970s (Lévi-Strauss, 1949/1969; Needham, 1971; Radcliffe-Brown, 1952; Schneider, 1984). Anthropologists, in particular, have made great strides in rethinking how families are formed through various processes of kin-making and unmaking, drawing on the rich data derived from Western examples, where rapid social change necessitated and facilitated a move away from heteronormative, biogenetic, and strictly patriarchal modes of living and caring (see, e.g., Carsten, 2004; Ginsburg & Rapp, 1995; Inhorn & Birenbaum-Carmeli, 2008; Strathern, 1992, 2005). Societies in the Global North are increasingly fluid, and the nature of the family has changed dramatically.

Despite what is often reported as firmly entrenched and reified cultural beliefs, and continued emphasis on lineality and patriarchal structures in local rhetoric (Block, 2014), kinship in societies in the Global South is equally fluid. Yet as articulated in state policy and programs – or as tacitly implied by the lack of other options – there is still a common assumption that kin will provide care for those in need. This is especially so in low-resource settings, where states lack the capacity to provide institutional alternatives, and where it is frequently assumed that kinsfolk are morally and socially obligated and thus will step up to provide care (Akintola, 2006; Foster, 2000; Seeley et al., 1993; Shawky, 1972).

HIV/AIDS, however, combined with demographic and economic changes to families, has brought into sharp relief the ways in which families are made and unmade in unexpected ways. As we illustrate in this issue, families everywhere are flexible, and have to be so to be resilient in the face of economic, political, social, and personal forces.

The unifying concern of the families and communities represented in this issue is the impact of HIV/AIDS on their everyday lives. However, HIV is now a chronic illness, co-existing with other conditions, and AIDS is not most people’s primary concern. Rather, people are concerned with a wide range of questions around livelihood, sociality, and relatedness; HIV and AIDS shape and underpin many of these relationships. Our aim in this
collection is to tease out the different ways in which care is distributed, so as to illustrate how families and communities provide care and support to people infected with and afflicted by HIV.

Care is a deeply personal and intimate labor of love, obligation, and social reproduction, and we begin this introduction by grounding our interests in the lives of people as they are influenced by HIV. The following excerpt is from Ellen Block’s field notes of a young child who she came to know in Lesotho. All personal names are pseudonyms.

Kananelo Mohlomi was born in South Africa in 2005 to a Mosotho woman called Lebo. Lebo had moved to KwaZulu Natal four years prior to find work; her husband, 20 years her senior, stayed behind in the highlands of Lesotho. Kananelo was only 21 months of age when Lebo died of AIDS. Although the family did not have the money to bring Lebo’s body home for burial, an uncle travelled to South Africa to bring Kananelo home to her maternal grandmother in rural Lesotho. When she arrived, Kananelo weighed less than 5 kg; her skin was wrinkled and desiccated; her eyes deeply set in their sockets. She showed signs of both advanced AIDS and TB. She was wasted and despondent. She had no appetite, and had consumed only water for the previous few days. What little food she ate gave her diarrhoea. Her breathing was shallow. She had an ear infection that produced a putrid smell. Her grandmother thought her death was inevitable, and she simply wanted the child to return to Lesotho to die in the midst of love and care from her family. But other family members convinced the grandmother to let her go to the hospital. There, Kananelo started ART and TB treatment regimens. She slowly regained her health and returned to her family after several months.

While she was in hospital, Kananelo’s grandmother died. Kananelo’s mother’s estranged husband, Ntate Rorisang, was not her biological father, and he was in his 60s, but he accepted Kananelo as his daughter because his social role as father outweighed any questions of paternity. At marriage, he had paid Lebo’s family lobola (bridewealth payment) of seven cows, giving him both rights and responsibilities to the children born to her.

For almost a decade now, Kananelo has been living with Ntate Rorisang in a village in the mountains, with other grandmothers, aunts, and uncles – some consanguineal kin, others not – helping to care for her.

Everywhere, people negotiate with others as they determine who should provide care for those living with or otherwise affected by HIV. In this issue, we are concerned with how care responsibilities fall to some family members and not to others, and the mix of pragmatic decision-making and fortuity that influences this. We examine how families work around the limits of their personal capacities and economic contingencies to provide care, and how institutional and structural factors define what can be provided under the rubric of care in different environments.

Kananelo’s story illustrates only one way in which kin might respond to a crisis precipitated by AIDS. Her story has an apparent happy ending – she is embraced by her mother’s consanguineal and affinal kin – but it need not have taken this turn. The circumstances of Lebo’s migration, infection, and death, and Kananelo’s near death, draw attention to the ways that demographic shifts and socio-economic realities in low- and middle-income countries have altered family relations and social dynamics. These effects reverberate meaningfully, and sometimes painfully, through relations of care and responsibility. In southern Africa – from which most of the articles in this issue derive – social and economic life over the past several decades has been characterized by high rates of labor migration, increased marital dissolution, a rise in both the numbers and acceptance of children born outside of recognized unions, and as a direct result of HIV infection and AIDS, lowered life expectancy. The exceptionally high incidence of HIV and its continued transmission, despite three decades of public health and medical interventions, continue to have a significant impact on families. HIV has cut into family life wherever people are infected, requiring individuals, households, and communities to reimagine caregiving and social responsibility to others (Majumdar & Mazeleni, 2010). As Dawson (2013) illustrates, the extended family, where it is sustained, can no longer be regarded as a certain “safety net” for caregiving or for other social or economic purposes.

Kananelo’s situation also captures some of the tensions that exist between idealized forms of social relations and the increasing flexibility required to respond to the care needs of extended kin. Kananelo’s family was able to respond flexibly, in ways that illustrate the richness of the local kinship networks in the study setting, but also the capacity of people to interpret and use cultural conventions to their own ends. Here, the bridewealth payment at marriage established the responsibilities of kin for a small child who was effectively orphaned. In other settings, motives to provide care may be determined by family circumstances and individual family and gender-based values (Ainkotola, 2006; Opiyo, Yamano, & Jayne, 2008; Orner, 2006; Shefer et al., 2008). Although women may be expected more often than men to take on care work, shifting circumstances shape dependency, care needs, and caregiving. In poor urban and rural environments, and in households where parentage may be unknown or unacknowledged, there may be less robust networks of kin or other available and willing adults (Kang’ethe, 2009; Moyer & Igonya, 2014). In settings where
everyday circumstances are shaped by physical distance from services, social isolation, poor infrastructure, and absolute poverty, people may lack the networks and the resources to assist in providing the most basic care and support.

Worldwide, HIV and AIDS affected populations enormously in the first two decades of its transmission, as men and women of productive age were diagnosed and rapidly fell ill and died. Many of those deceased were never counted as having died from AIDS, because of the stigma to the individual and family, and because a positive test was seen as a certain death sentence. Antiretroviral therapy (ART) has proven a turning point in the trajectory of the illness, and while effective prevention appears still to be elusive, HIV is (in 2016) in most cases a chronic condition. The increasing routine introduction of ART at the point of diagnosis ensures that people will potentially live long lives despite their infection as long as access to treatment continues to expand, and those who accept and remain on treatment are unlikely to transmit the infection by any means. Yet while the health outcomes of those living with HIV have much improved, the disease continues to have a great impact on populations, including nuclear and extended family systems, informal care networks that extend beyond families, and formal institutions and health care providers.

The necessary medicalization of everyday life with ART means that there is an expectation that the person with HIV will require self-care and care by others within his or her network: to monitor adherence to medication, to monitor general health, and to treat other diseases (tuberculosis especially). Personal behavior is part of the field of the surveillance of those with AIDS, so to reduce risks to self and others (of reinfection, or of other infections). But as Whyte (2009) has argued, they are not “simply” patients; their lives extend beyond clinic doors. People living with HIV are also members of families, support groups, and communities, and their health impacts the lives of those in their close social networks and beyond. From within these webs of supportive kin and non-kin, formal and informal arrangements emerge for the provision of care, with labor divided depending on the specific capacities of its members. Care work for those living with HIV can be arduous, depending on the health status of an individual; it can include personal bodily care, child care, the provision and preparation of food, household chores and maintenance, assistance with transportation, medical appointments, assistance with finances (paying bills and lending money), and social activities. Patients and families must extend and redefine caring relationships to provide a range of support and assistance.

As the authors in this issue illustrate, kin relationships that contribute to such care are neither prescriptive nor predictive. Family caregiving may be an extension of the reciprocity that shapes family relationships, but as we have noted above, gender and specific kinship relationships influence who takes on care work. Wives are more likely to provide care for a spouse than husbands, though some men do care for their partners. Daughters are more likely to take on care work than sons, and grandmothers provide substantial care for their sick children and their grandchildren, whether or not infected. Children too often take on the responsibility of providing personal care (Andersen, 2012). Wider networks are also often brought into the fold, including the siblings of primary caregivers or care recipients, grandchildren, and other older people – we illustrated this above for Kananelo. However, as demonstrated by some of the authors in this issue, sometimes there are no kin to care for people who are sick, or none able or willing to take on the long-term care work of children orphaned by HIV. Sometimes, families consider the cost of time out of work to be too great, and so they must privilege the continued well-being of all household members over the everyday needs of one person. And sometimes friends, community members, or health workers are asked to – or attempt to – fill this niche. Churches throughout the region have contrarily both stigmatized and excluded people with HIV (Campbell, Nair, Maimane, & Sibiya, 2008; Goudge, Ngoma, Schneider, & Manderson, 2009) and provided many of the volunteers working with people in greatest need (Akintola, 2010, 2011). Klaits (2010) has shown how church members in Botswana can sometimes take the place of kin – and at times act like kin – to perform the many tasks required for a dying person. Igonya and Moyer (2016) illustrate this mutual support in their description of a group of Kenyan HIV-positive men who have sex with men. These men support each other during illness, yet they also care for each other due to other social vulnerabilities, particularly in the absence of supportive families and in the context of a hostile wider community. A number of papers in this issue also emphasize this point. For example, Casey Miller examines support networks of gay men in China who willingly provide support and care for each other. Likewise, Nonhlanhla Nxumalo, Jane Goudge and Lenore Manderson show how sometimes no kin – fictive, affinal or consanguineal – are available, and such people may be dependent on community health workers to fill the gaps.

This issue begins with a unique contribution to the growing literature on kinship and care in the context of the continuing transmission of HIV. Fortunate Shabalala, Ariane de Lannoy, Eileen Moyer, and Ria Reis...
present five case studies that illustrate the diverse experiences of family, care, and belonging among HIV-positive adolescents. These young people live in Swaziland, a country with one of the highest HIV prevalence rates in the world and where more than two-thirds of the population lives below the poverty line. What emerges from their study is the importance of biogenetic connections: this shapes who are considered “family” and who are not. In contrast to most of the papers in this issue, Shabalala and her co-authors show how kinship in this context is interpreted as inherently inflexible, narrowing instead of broadening the possibilities for appropriate care. In teasing this out, the authors highlight the methodological as well as ethnographic significance of their work, as they point to the importance of working with and learning from young people of their experiences and desires regarding family, belonging, and care. It is perhaps a caution against romanticizing the willingness to care, and not to ascribe the values and beliefs of older generations to those of younger ones.

In southern Africa and elsewhere, the voices of adults dominate discussions of care, including in deciding the best interests of the child or children. Sometimes kin take on this task with apparent enthusiasm, but often this has multiple motives. Dahl (in press) and Reynolds (in press), for example, both draw attention to the significance of the monetary compensation that kin may receive to care for orphans. In both their studies, state subventions provide a motive to care as much as they compensate sometimes distant kin for the “costs” of care. Further, as Sonja Merten illustrates in this issue, in Zambia, those who are available to provide care, the nature of the care they can provide, and the conditions under which this occurs varies on the basis of pragmatism, sentimentality, and happenstance.

As Shabalala and her co-authors show, young people in Swaziland emphasized biogenetic connections in creating family and belonging. But the responsibility of caring for young people varies by social and economic context and cultural convention. Most societies have rules about who should care for children and in the majority of cases, everyday caregiving is relegated to mothers and other female kin. Southern Africa increasingly has a feminized labor force, with women migrating away from their families in search of work and remitting funds to support those left behind, including their own children and others. In such contexts, resources are central to decisions about who provides, and if, when, and how care is provided.

Knight, Hosegood, and Timaeus (in press) illustrate this in considering the different motives to care for kin in KwaZulu Natal. By extending the definition of care to include financial support and in-kind assistance, these authors show that people still uphold particular kinship-related care obligations. In their rural research setting, where employment opportunities are scarce, out-migration is both common and necessary, and families must balance the decision to earn an income to support all members of the family against the needs of particular individuals for everyday health supervision, personal care, and social support. Knight and colleagues are concerned with evolving ideas of responsibility and obligation that underlie decisions around caregiving, and highlight that while some decisions may derive from physical and relational proximity within webs of relatedness, other decisions are strategic and conditional.

We know little of what happens in families when women are not around to provide care for children because they have died from AIDS or have migrated for work. Ellen Block shows how in Lesotho, in the absence of female caregivers, men are increasingly taking on the role of providing care for children affected by HIV/AIDS. This deviation from the ideal that women should care for their children has not translated to a change in the discourse about care responsibility; women remain the preferred (and primary) caregivers and care is often spoken about using feminized discourse. The emergence of male caregivers, Block suggests, is a consequence of larger structural issues and demographic shifts which have manifested in the increasing difficulty men face in finding work and their diminished ability to provide for their families (Shefer et al., 2008; Spiegel, 1981). It also occurs in the context of the dwindling numbers of AIDS-free grandmothers, as the HIV-affected population ages (Negin & Cumming, 2010; Negin, Mills, & Bärnighausen, 2012).

The entanglement of health and care with global politics and larger socio-economic issues runs thematically through all articles in this issue, but it is particularly pertinent in Sonja Merten’s consideration of family and care in Zambia. With the changing salience of kinship and changes in household structure consequent to urbanization, and Westernization, Merten writes that sibling obligations no longer pertain, and siblings are far less likely now than in the past to provide care to someone with AIDS, or for any other reason of frailty, illness, or limited capacity to self-care. This, she suggests, is not because of the changes in how families are created, but because of the dilution of mechanisms of accountability, which previously compelled family members to assume care responsibilities. There has been a presumption that families will provide care for people living with AIDS, but relatives are not always willing or able to do so. Given the unpredictability of care, people attempt to build up care capital by shaping interpersonal relationships through economic, social, and affective bonds.
From these examples, we turn to other relations of care, as provided through communities, health services, and self-care. In his article on HIV-positive gay men in China, Casey Miller illustrates the importance of care provided by people outside of kinship networks. Stigma, exclusion, and discrimination continue to shape the everyday life of gay men in much of China, and widespread and institutionalized homophobia continues. Men with HIV infection necessarily have to manage the double burden of stigma as a result of sexual identity and same-sex unions, as well as their HIV status. These men need to make their own families, and various NGOs function as alternative families of care. The networks that arise from these NGOs extend beyond the practical provision of everyday care and support; they also take on advocacy around moral and political agendas. Like the gay men’s community-based organizations and social networks that emerged, notably in Australia, in the first decade of AIDS (Edwards, 1990/2004; Power, 2011; Whittaker, 1992), in China, the voluntary caregiving that gay men undertake for each other becomes simultaneously a process of caring for others and caring for the self. Caregivers and care recipients provide reciprocal support; caregiving is never unidirectional.

The care that people provide to each other flows from the affective quality of their personal relationships – as husband and wife, for instance, or mother and son. Relationships of care largely exist because of the emotional commitment that people have to each other, even (or especially) in the context of calculations of the costs and benefits of caregiving, and the exigencies of time, proximity, and resources. But the kind of care people provide to each other is largely determined by capacity, as illustrated in the examples presented by Nxumalo, Goudge, and Manderson. In their cases, people are limited in their ability to do the work of care because of geographic isolation, material deprivation, acute poverty, lack of access to goods and services, and their limited capacity to negotiate the bureaucracies that might provide resources.

Where resources are limited, community health care workers play a critical role. However, in South Africa, bureaucratic and structural obstacles limit the assistance they can provide (Akintola, 2008; Schneider, Hlopre, & van Rensburg, 2008). Ironically, in the better-provisioned of the two provinces that these authors discuss, health workers did not feel that they had the resources at their disposal to address the needs of those most marginalized; in the poorer of the provinces, the health workers were able to mobilize support at either community or government level to draw attention to people’s problems or to solve them directly. To some extent, this was possible because of the willingness of the community health workers to invest in building relationships with their clients, so to establish relationships of trust. In public health terms, this increased the possibility that people would take their advice, thus increasing their effectiveness in providing primary health care. But the need for community health workers to mediate between the formal health care system and marginalized populations is particularly important, given that structural and human resource challenges limit the effectiveness of the primary health care system. Community health workers can and often do provide important services that the formal health care system is not able to. At the same time, as Kalofonos (2014) has illustrated in Mozambique, the demands placed on community health workers can often be overwhelming, leaving them frustrated and with a sense of exploitation.

The final contribution of this supplement takes us back to people living with HIV, or those “at risk” – that is, all people – and so explores a different kind of care – care through empowerment. Jessica Ruthven discusses the attempt of theater makers in South Africa to heal what she sees as a “disconnect” between policy, programs, and target audiences. Her argument is based on a critique of the persistent didactic nature of HIV health education and health promotion programs in South Africa and elsewhere. People are admonished to use condoms, be faithful or abstain, and by so doing, they care for themselves and for others. However, the continued transmission of HIV demonstrates the limits to the success of these directives. Ruthven locates this disconnect of policies and everyday self-care in the inability and unwillingness of those shaping such policies and implementing programs to enable people to make their own decisions about health-related action. The majority of programs, she argues, are premised on an idea of a responsible individual who invests in self-care and self-regulation – a neoliberal ideal inadequately transported to other, often marginalized, populations and settings. Because these messages lack coherence and fail to speak to people’s everyday experiences, the “care” that is delivered through these programs has the potential to be uncaring. According to the theater educators and advocates with whom she has worked, people are more likely to follow a course of action after weighing up their options and bringing their lived experiences to bear.

The authors of these articles illustrate a number of trends in care for family members impacted by AIDS. Women are most likely to provide continuous care, and non-related women are most likely to provide other support. However, men also provide active support and care for partners, siblings, and fostered or biological children. In the context of HIV, informal caregiving within the family and from wider kinship networks are
supplemented by the engagement of community health workers and others in social networks. In doing so, caregivers often experience considerable pressure – a combination of emotional strain and the time and physical effort required for personal care. The immensity of these pressures help to explain the significance some people give to state support for care, in low- and middle-income settings as much as in high-income countries, and reinforce the need to develop public policies and practices to enhance the welfare of caregivers and care recipients. Yet more important than these specific trends in care are the ways in which the many ethnographic examples in this issue point to people’s context-specific interpretations and flexibility in managing care relations: people draw on kin and non-kin, they interpret relations as more or less flexible, and navigate their social environments in anticipation of the future possibility of needing to provide or receive care. By attending to the relationships of care giving and receiving that are formed around HIV, and the limits to both formal and informal care in many settings, we gain a better understanding of the continuing reverberations and resilience required in households and communities with the ongoing and aging epidemic.

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