Monitoring the body: grandmothers' ability to provide 'expert' care for grandchildren living with HIV in northwest Tanzania.

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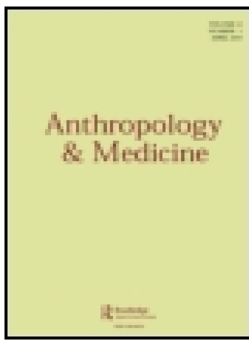

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Monitoring the body: grandmothers' ability to provide 'expert' care for grandchildren living with HIV in northwest Tanzania

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ABSTRACT
Drawing on long-term ethnographic fieldwork on older caregivers and their shifting roles since the introduction of antiretroviral therapy in northwest Tanzania, this article explores grandmothers' roles in caring for grandchildren who are HIV positive and on treatment. While AIDS treatment programmes usually focus on cultivating expert *patients* who can perform self-care, this study focuses on older *caregivers* and how they become experts in caring for their grandchildren living with HIV. How is expert care enacted and what supports or limits its quality? Based on observations and in-depth interviews, this article argues that grandmothers become 'expert caregivers' by merging knowledge acquired in the clinic and support groups with intimate practices of grandparental care. However, the grandmother's gendered and generational position within kin networks affects her ability to provide expert care. The findings indicate that in analysing treatment outcomes among adolescents, it is important to understand the broader family dynamic that influences the actual possibility of expert caregivers to support children living with HIV.

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Expert care; grandmothers; HIV + adolescents; Tanzania; family care; surveillance; HIV/AIDS

Introduction

> She went to the river this Saturday with a blanket [to wash], it was very heavy. I watch how she does that work, if she can manage. And when she goes to the clinic I ask the nurse: 'Has she improved, has she added [weight]?' And at school I ask if she gained [weight].
>
> (Rosa, 68, caring for 17-year-old Agneta)

'Weight' and 'ability to work' circulate in older grandmother's narratives of monitoring the bodies of their grandchildren living with HIV on antiretroviral therapy (ART) in northwest Tanzania. These two very different metrics both 'measure' care, but in different ways. 'Weight' is derived from scales used in institutions such as schools and clinics to convert the 'homework' of self-care (Meinert 2013) into numbers that carry a specific significance: is this person or caregiver adhering to ART? This is the 'measured body', as Whyte (2014) calls it: the use of an objective metric that subtly conceptualises the body in a specific

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narrative of progress. Weight gain as an indicator of improving health on ART also extends to relations of care; it signifies good care. It translates the lifestyle messages that accompany ART – eating well, no alcohol, pacing life, no unsafe sex – into something tangible.

These objective measures introduced by treatment programmes are incorporated into the 'lived body', the way we experience the world through our bodies, and how the body and its appearances also shapes how others react to us (Whyte 2014). Weight becomes a metric that defines not just medical progress but also the way others perceive the person as a socially embedded person; weight becomes a signifier not just of the quality of self-care but also of the *care* received by others. Because grandmothers have an embodied experience of caring for dying relatives, who wasted away, in the period before antiretroviral treatment, weight gain for them also carries significance.

The other metric, 'ability to work', is not measurable with scales or diagnostic tests but equally valid for grandmothers as a signifier of good care and progress. In northwest Tanzania, the ability to do work – to have a strong enough body to participate in routine living and fulfil obligations – makes someone a socially embedded person. Especially in northwest Tanzania, the precarity of everyday survival places an emphasis on the 'able body' (De Klerk 2011). As with weight, bodily ability becomes the signifier of care that is not just aimed at medical progress but explicitly at social belonging.

This article discusses how grandmothers provide care to grandchildren living with HIV and how, within the everyday care they provide, they routinely combine different forms of expertise derived from the clinic and from NGOs with values of grandmother care. Grandmothers are often the most stable caregivers in severely strained kinship networks, and their care is marked by affection and efforts to create continuity (Block 2012; Shabalala et al. 2016). 'Grandmother care' then has broader aims than just ensuring physical health and adherence: it is geared towards social inclusion. While patients in treatment programmes in sub-Saharan Africa have been described as self-disciplined 'experts', who care for their bodies with the help of others (Whyte 2014; De Klerk and Moyer 2017), it is the caregivers and what can be called 'expert care', that is the focus of this article. What does expert care entail and what shapes or hinders its enactment?

Adherence to ART, essential for virological suppression (Cherutich et al. 2016), is seen as one of the challenges children living with HIV face. Adherence seems to be poorer in children who have not yet been told their status, but adherence is also affected by stigma, hunger, food insecurity and lack of psycho-social support (Shabalala 2017, 171). Adherence, in other words, is deeply social (Mattes 2011), and family care directly influences treatment outcomes (Shabalala 2017). Given the challenges to linkage and retention in care faced by the Tanzanian healthcare system, and the explicit mentioning of the influence of caregivers on adherence among children and adolescents in Tanzania's National Guidelines for the Management of HIV/AIDS 2017 (NACP 2017, 238–245), it is increasingly important to understand the work of caring for children living with HIV and how family dynamics may affect treatment outcomes (Dlamini-Simelane and Moyer 2016).

This article not only brings grandmothers as expert carers into focus but makes explicit how a grandmother's social position within the kinship network shapes her ability to care. Skovdal et al. (2011) write that we should take seriously the challenges grandmothers face in caring for grandchildren living with HIV. Grandparents may work to facilitate their grandchildren's adherence to treatment, but may themselves be in poor physical and psycho-social health, leading to grandchildren living with HIV providing care to them

(Rutakumwa et al. 2015). A grandparent's lack of resources to provide food, memory issues and insufficient family support also may influence adherence (Skovdal et al. 2011; Rutakumwa et al. 2015). Grandmother care is not only about the grandmother–grandchild dyad, it is also about others who are present where care takes place (Block 2016). In taking this approach, the article follows recent calls to pay attention to differences in the familial contexts of children living with HIV (Shabalala 2017).

In analysing grandmothers as expert carers, I suggest that while the progress and decline of the HIV-positive body is directly linked to the social relations in which the body is embedded (Whyte 2014), the ability to provide care for a grandchild's HIV-positive body is also linked to the social relations in which the carer is embedded.

Expert caregiving

Central in this article is the concept of 'monitoring' as core practice of expert care. Monitoring has been often described in terms of the 'surveillance' HIV/AIDS treatment programmes carry out, through expert clients. Here surveillance is part of ensuring population health, through the widespread use of measuring techniques that objectify and quantify 'health' (Whyte 2014, 235). Much research has focused on the involvement of patients in surveillance, and how treatment programmes socialise patients into becoming responsible, adherent patients who share an illness-based identity, with particular biomedical and lifestyle knowledge and modes of speech; the 'expert patient' (Kielmann and Cataldo 2010; Nguyen 2010). Another body of literature discusses the 'expert patient', as a cadre of volunteers who may fill important gaps in the healthcare system (Kielmann and Cataldo 2010; Kyakuwa 2010; Kyakuwa, Hardon, and Goldstein 2012; Moyer 2014). In this literature, 'monitoring' refers to assessing the measured body through routine check-ups at healthcare facilities (Moyer and Hardon 2014; Whyte 2014). This article builds on the notion of expertise as central part of surveillance/monitoring, extending the focus to expertise in care.

In chronic illness management, 'monitoring' has another meaning: the continuous self-monitoring of physical health that is part of living with a disease that fluctuates (Swendeman, Ingram, and Rotheram-Borus 2009). Monitoring as part of care is about the careful observing, the watching over, that is attuned to the needs of the body (Mol 2008). Physical progress, as the outcome of monitoring, is dependent on family factors, including a grandmother's ability to navigate the kin group involved in or opposed to certain forms of care. The broader question, how both forms of monitoring merge into everyday care work in families, suggests that the 'measured body' is always contextualised in terms of the values of social life (Whyte 2014, 235). What remains a question is *how* this monitoring of the social body takes place and how monitoring translates into care practices.

Research setting

This study took place in Nshamba, one of the main market towns of the Muleba district in Kagera Region in northwest Tanzania. Kagera Region is home to the Haya. Bordering on Uganda to the north and Lake Victoria to the east, Kagera Region was hit hard by the Ugandan HIV/AIDS epidemic, especially in the 1990s. When this study was conducted, in 2012, many of those who were in their late sixties had lived through the deaths of partners,

siblings, children and grandchildren; provided palliative care; and raised grandchildren before the introduction of ART in 2004 changed these realities of caregiving. While the introduction of ART in Kagera Region brought about an era of '*nafuu*' – a quiet coming to terms with 25 years of loss – it merely changed palliative care into chronic long-term care and (self-) care for people living with HIV.

Grandmothers acquired expertise of HIV through years of caring and witnessing adult death and have melted this embodied knowledge with two forms of 'official expertise'. First, global health perspectives on HIV and policy circulated through the counselling services and support groups linked to the AIDS care and treatment centre (CTC) located in the nearby district hospital. Upon a positive test result, patients went through 'education', in which counsellors discussed adherence, proper nutrition, social inclusion and the need to pace work. Adults and adolescents were told their test results directly and underwent education themselves, but when young children were found to be HIV positive, their caregivers were told the results and were the ones to meet with counsellors.

Grandmothers gained additional expertise through their involvement in a local organisation for orphaned children: Kwa Wazee [for elderly]. At around the same time as ART was rolled out in the district, Kwa Wazee began distributing a monthly stipend to an initial group of about one hundred older caregivers. Founded by a Swiss child psychologist, the organisation also provided psycho-social support; Kwa Wazee's discussion groups focused on the everyday challenges of raising grandchildren, child development and conflict resolution. In 2017, the organisation had 1103 older beneficiaries, and its services included a health programme, a savings programme, an income-generating and social solidarity programme, and a legal programme. An additional programme on training both children and adults living with HIV was added after the introduction of antiretroviral treatment. While most children living with HIV that were a beneficiary of Kwa Wazee were living with their parents, in 2016, 27 children living with HIV were living with grandparents.

Methods

This article was part of a broader postdoctoral study on the changing social institution of kinship in the era of ART treatment in northwest Tanzania. Constructed as a follow up on a PhD study on ageing and care in the pre-treatment era (De Klerk 2011), this study traced how the introduction of antiretroviral treatment had changed care practices in intergenerational relations in Muleba district. In 2012, the author conducted six weeks of fieldwork including in-depth interviews with respondents who had particular care roles: older people caring for children or grandchildren living with HIV, in order to understand how care tasks had shifted from palliative to chronic care, and adults living with HIV between the ages of 40 and 65, in order to understand the challenges of combining caregiving and self-care with an ageing/chronically ill body. In addition, observations and focus group discussions were conducted with Kwa Wazee support groups to understand the broader challenges of living with an ageing body today. To recruit participants for this study, the health coordinator of the Kwa Wazee project approached grandmothers caring for grandchildren living with HIV and asked for permission to visit with the researcher. While the initial sample strategy was based on convenience, the choice for the four vignettes that form the body of the article was purposive, based on the unique perspective the case could add to the study.

While this article highlights only the data obtained from the in-depth interviews with grandmothers of adolescents living with HIV (six in total, see Table 1),[1] it uses the insights from the other interviews, observations and focus groups as context for the analysis. Indeed, many themes around living with and caring for a chronically ill body in the context of family dynamics were similar across the broader group of participants. The author's knowledge about ageing and kinship care, obtained through long-term fieldwork between 2002 and 2004 with follow-up visits in 2005 and 2008, informed the discussion of family dynamics in grandmother care.

The interviews for the vignettes were conducted in Kiswahili, with the presence of a trusted staff member of Kwa Wazee who translated when grandmothers spoke the local vernacular, Kihaya. Grandmothers were first informed of the author's previous research and her interest in understanding how grandmothers looked after their grandchildren, after which a conversation on the home and family situation eventually led into questions about more sensitive topics such as care, monitoring and food. While the interviews were unstructured, a topic list ensured that all grandmothers were asked the same questions. All interviews were audio-recorded and transcribed, read several times and coded for information related to care activities, the ageing body and family situation.

Recruiting participants through Kwa Wazee was a conscious choice for ethical reasons and reasons of access; the sensitivity of this subject needs long-term relationship building. There was a trusted relation between the Kwa Wazee member and the grandmothers which allowed for in-depth contact. The researcher made sure that the questions were mostly related to everyday practices and observed how older people spoke about challenges in the presence of the Kwa Wazee staff member. Their participation in Kwa Wazee meant that many older caregivers had received psycho-social support in solving intergenerational conflicts in addition to the adherence trainings provided by their enrolment in the CTC. This article treats both Kwa Wazee and the CTC as interventions that spread particular knowledge that was then merged with existing practices of grandmother care. However, a focus on those who have participated in such activities might obscure the many cases where elderly caregivers fail to provide expert care for a variety of reasons (Block 2016). While this article should not be taken as an indication that all grandmothers always provide expert care, it shows what expert care from grandmothers looks like in this particular context.

Table 1. Family situation of grandmothers' caring for grandchildren living with HIV.

Name	Age	Caring for HIV + grandchild	Kinship relationship to HIV + grandchild	Family situation
Robina	71	Mary (5)	Maternal grandmother	Household head, lives with young HIV + and HIV- grandchildren of divorced daughter and deceased son in household
Anamary	67	Jovinatha (17)	Paternal grandmother	Married, Jovinatha's parents are still alive but HIV positive
Rosa	68	Agneta (17)	Maternal grandmother	Divorced, lives with HIV + and HIV- grandchildren in brother's home
Joyce	64	Jafali (16)	Maternal grandmother	Household head and living with children of deceased children
Efarista	67	Emanuel (13)	Paternal grandmother	Household head, living with grandchildren from two deceased children
Agneta	72	Livia (16), one half of a twin	Paternal grandmother	Household head, lives with grandchildren, both orphaned grandchildren and grandchildren sent to live because it is close to school.

Expert carers: four vignettes

Monitoring through closeness: Robina and Mary

Sitting and waiting in the shade outside the Kwa Wazee office building, the subtle intimacy between Robina, 71, and Mary, 5, is striking. Robina constantly looks at Mary, caresses her and lifts her to her hip, always keeping bodily contact. Mary has lived with Robina since the age of three; Robina also cared for Mary's mother who came home from Mwanza Region and was ill for a year. Mary's mother was brought to Rubya Hospital to start treatment but her illness was so advanced that it was too late. When telling this Robina starts crying and seeing her cry, Mary cries too. Robina also raises the six healthy children of her deceased son and her divorced daughter.

Robina monitors Mary's health through *physical closeness*. She sleeps with Mary in one bed so she can detect fevers immediately and, on clinic days, she carries her on her back, all eight kilometres, getting up at 4 in the morning to be on time. Robina's age and infirmity means caring for Mary is difficult. Her other grandchildren sometimes help her carry Mary. Sometimes when she has walked too slowly, Robina misses Mary's appointment and has to stay in the hospital overnight, but she says it is her 'duty' to go, no matter what. At the same time, care exhausts Robina. Only a few weeks ago, she stayed at home for 30 days in row, not even going to the market, because Mary could not stop coughing and had a fever.

Robina combines the clinic's advice about food that builds health with common grandmotherly sense. She tries to give Mary fruit, porridge and things that Mary really likes, like rice, but most importantly she never restricts Mary to the usual two meals a day. While she also took this approach for her other grandchildren, she does make the other children understand that Mary needs extra food. Mary receives two cups of porridge and a whole egg, rather than a half egg. But the most important thing in raising a child with HIV, she says, is to stay close to that child, cleaning her, and covering her well. Robina tries very hard to make Mary not miss her mother. Robina feels stress sometimes; she does not have much strength and her back is paining her. She finds relief in talking to other grandmothers in the CTC on clinic days. Robina, having cared for her daughter who started therapy in an advanced stage of her disease, has always understood that ART should be started when the disease is advanced. She is confused and worried by the CTC's changed policy that ART should be started when people living with HIV are still in good health. At the CTC, they told her that her granddaughter is in better condition than her mother was, so why start with these medicines already?

The responsibility of monitoring: Anamary and Jovinatha

Anamary (67), together with her husband, cares for their granddaughter Jovinatha who is 17 and HIV positive, and who has lived with them since she stopped breastfeeding as is common in Kagera. Jovinatha's parents are still alive but are also HIV positive. Jovinatha is the daughter of Anamary's son and has a special place in Anamary's heart: 'I care about her a lot, I see that she is the one remaining alone, the others she was born with died'. Care for Anamary, as she explains in the quote below, means looking after Jovinatha's well-being, making sure she eats well: 'food' (referring to the staple, plantain), tea, and *dagaa* [small fish], and occasionally meat. Special foods are more difficult to obtain; she has not been able to buy milk for a while and sometimes arranges for avocado to be sent by public

transport from the regional capital Bukoba, where they are cheaper. But it is peanut season now, and she also has spinach and papaya, and that is what she gives Jovinatha. She makes sure that Jovinatha has more food than the other granddaughter living with her.

> Even though it has never been a lot of work to care for her, because she was never really ill, of course caring for grandchildren who are affected is still more of a burden, because you have to look for good food to give her, the one they advised in the hospital, you have to check whether she takes the medicine or not. You have the responsibility to look after her more than you look after the one that is not ill.

Anamary makes sure that Jovinatha takes her medicines and she knows Jovinatha is not hiding them (as other young people are reported to do); Anamary goes into her room to count them. Jovinatha only started taking medicines two months ago when she started to lose weight and become ill more often. Jovinatha knows her HIV status and says that she probably got it from 'drinking the milk of mama'. She was told that she was HIV positive from the moment she went to test. Jovinatha now goes to hospital every month on her own; Anamary notes that she was 'educated' there, after all. Jovinatha struggles with social exclusion at school: after a hospital employee spread the news of her positive test, her fellow students started hissing at her. Anamary responded by trying to guide Jovinatha towards her future, and getting her to focus on finishing school. Anamary hopes for Jovinatha to marry, but she advises her not to engage in sex, as she learned at the hospital that sex adds to the virus. The unpredictability of chronic HIV worries Anamary though. She is never sure whether her grandchild and children will survive: 'Will God take them or will they stay here? But I let go of those worries'.

Monitoring through observing physical strength: Rosa and Agneta

Rosa, a divorced woman of 68, cares for the daughter of her deceased daughter, Agneta, who is 17 and has lived with her since she was very young. Although Agneta's mother only died when Agneta was ten, she was, as Rosa says, marrying many husbands, running around and getting pregnant, and so Agneta was already living with Rosa before her mother died. Agneta is HIV positive and on antiretrovirals (ARVs). She takes all her medications; her grandmother monitors her vigilantly. She sleeps with Agneta in the same room, where they also store the ARVs so she can watch her take the tablets in the morning and evening. To monitor her body, she watches how Agneta works, to see if she is able to physically carry heavy loads. In the opening to this article, Rosa is quoted, describing how she watches Agneta carry the laundry to the river, to see how her strength is holding up, and how she asks the clinic and the school about Agneta's weight, in the hope that she is gaining.

Rosa worries about Agneta's future, in particular marriage. But the only thing she tells Agneta is to not get pregnant, as talking about sex is too difficult. Sitting in the living room of Rosa's brother's house, she explains that she feels she is failing to care properly for her granddaughter because she cannot give her sufficient food and cannot ensure that she has a reasonable amount of work. As a guest in her brother's house, Rosa's sister-in-law decides on the distribution of food and on who should do what work. Sometimes Agneta does not eat breakfast, and Rosa tries to scrape some money from her Kwa Wazee pension together so Agneta can buy some food at school because without food the medicines make her dizzy.

But money is a problem. Although Agneta eats meat regularly, she has not eaten milk and eggs for almost six months. The biggest problem, however, is the isolation at home. At the clinic, the counsellor told Rosa that there was no problem sharing soap and sleeping in the same bed and that the important thing was to not isolate Agneta. But her sister-in-law shuns Agneta, refusing to share plates, utensils and soap with her. Rosa says that she tries to stand up for her granddaughter but her position in this house and at her natal home is precarious; she herself was chased away from her natal home by relatives and this is the place where she was taken in. Rosa wants to build her own house and to just stay together with Agneta, so she can decide how much food to give her granddaughter.

Monitoring through 'looking': Joyce and Jafali

Joyce, 64, who walks with difficulty, cares for Jafali, her 16-year-old grandson who is HIV positive. She has been living with him since he was 5, along with three other grandchildren, from other children who died. 'They are siblings', she says, 'because they are all the children of my children'. Joyce took Jafali to get tested for HIV because he had difficulty breathing and had sores, but at that time medicines were not yet available so he just took Septrin for a long time. Then they checked his CD4 and started him on treatment. Now Jafali is doing well on treatment but suffers from a skin problem, which also affects him psychologically. She tries to treat it with special soap but it does not go away. Joyce says she cares for Jafali by 'looking'. While the clinic measures his weight, and she sees his progress in that way, she also looks at how Jafali functions: 'He lifts things, he does work when he comes home from school, eats food, and sleeps well, and after waking up at 5 am he prepares himself to go to school. So there you see progress'. Because Jafali is a bit tired of swallowing medicine, he brings them to her room in the morning so she can see him swallowing. 'He has his medications in a drawer, and his room is next to mine, so I listen if I hear him opening the drawer'. But she says care is also about monitoring in a different way:

> I need to look at him, because he has problems. You know those children who are affected. If you do not look after them, to love them [.] they will be more angry than other grandchildren would. In his thoughts it [the illness] is bothering him because he does not have an understanding that this is the illness. You assist him, take the worries, love him, give him this, tell him this, so that he becomes happy. Take the worries out of his head. […] I assist him with words. I ask him what he would like and if I have money I give it to him, and otherwise I tell him that I will search for it. I will tell him to not worry, and to just study, and he will be a grown man and will see his own house and wife and have children.

Joyce went to a seminar given by Kwa Wazee to learn how to talk to Jafali about sexuality and condom use and persisted in advising him, despite his obvious discomfort. But Joyce also has worries: she does not know how Jafali's future will be, without land from his father to inherit. Also, she explains, money does not always stretch enough to cover the costs of special food:

> We give green vegetables, a lot of beans and avocado, banana and eggs if you can get them. But it has been two months since he ate an egg. Sour milk he drinks, we buy it for 300 shillings, this week he drank it on Sunday. Meat on the national holiday, *Saba Saba* [7 July]. Every three or four days he eats it.

Results: 'expert' care

The care grandmothers provide to their grandchildren with HIV in essence does not differ from their care for other grandchildren, orphaned or not. What is considered 'good' care entails making sure the children are dressed well, have a warm blanket for sleeping, attend school, are fed well and especially are very clean, a sign of good care in Kagera (see also Block 2014). At the same time, grandmothers emphasised the extra care and attention they gave to their grandchildren with HIV, saying: 'it is my responsibility'. In what follows I discuss this responsibility and show how grandmothers' expert care merges advice from the clinic and Kwa Wazee with their own embodied knowledge and social values.

The aim of monitoring is to see physical progress. While the clinic measured physical progress in terms of improving CD4 count and weight, for older caregivers, physical progress also lies in their charges' ability to participate in everyday life. Although grandmothers all mentioned clinic check-ups when asked how they monitored physical progress, in practice they focused on the embeddedness of grandchildren: they observed how a child conducted routine activities, such as fetching water, collecting firewood and washing clothes, as well as their participation in social settings like school. Expert care was about making sure that children remained included in the household, did their share of work and obtained an education.

The vignettes showed that both physical progress and treatment adherence were monitored through everyday practices of closeness and careful observation. Often grandmothers shared beds with younger granddaughters living with HIV, and when granddaughters were older they often still shared a room. This made them intimately aware of any health changes. The vignettes show that being on ART did not necessarily mean a complete return to health. Living with an HIV-positive body required constant care and attention. Robina's granddaughter had bouts of illness, Joyce's grandson had skin problems, Anamary's granddaughter was unable to attend school at times, and Rosa's granddaughter had dizzy spells without food. Gender played a role in the methods grandmothers used to observe and maintain closeness: grandmothers could not share rooms with grandsons. Subtle techniques such as purposely storing the medicines in a creaky drawer so that it made noise when opened were ways to ensure adherence. These practices of observing and co-sleeping are normal practices of grandmother care; monitoring health and adherence become embedded into everyday normal routines between grandmothers and grandchildren.

CTC advice about life-style such as eating a special diet featured in everyday care practices. In their expert care, grandmothers merged new knowledge on what constituted good food (eggs, milk, fruit, meat) with the everyday socialities and values of eating. In Kagera, eating patterns do not match the needs of small children and especially children living with HIV. Main meals are at 3 pm and 9 pm, and breakfast is often a cup of tea. These intervals were considered too large for any young child to manage, and children living with HIV especially need to have access to regular food. Grandmothers tried to make sure that grandchildren living with HIV were always satiated: they cooked more food so there would be leftovers or provided money for snacks. In all but one of the vignettes grandmothers 'owned their own kitchen' and were empowered to make such decisions; Rosa, who was a guest and could not cook herself, circumvented these problems by giving her granddaughter money to buy food. While eating food is a social affair and food is shared, grandmothers made their other grandchildren aware of the special needs of the grandchild

who was HIV positive and the reason why they sometimes were given an egg or an extra helping. While providing special foods was often difficult given meagre resources, grandmothers worked with the seasonable availability of foods and navigated the social rules around eating.

Besides monitoring physical strength and progress – the main objects of surveillance in HIV care and treatment programmes, expert care included monitoring well-being. With long-term living also comes a sense of having a future, and grandmothers' expert care also entailed addressing worries, stigma, bereavement and social belonging. Kwa Wazee actively provided knowledge on bereavement, the parenting of adolescents and the specific needs of children living with HIV. The vignettes show that grandmothers were acutely aware of the potential mental health consequences of living with HIV, ranging from mourning the death of a parent to managing the disfiguring sores that give away HIV status, to being ostracised at school and at home. Counsellors in the CTC emphasised the importance of social inclusion for children and adolescents living with HIV, and grandmothers were encouraged to emphasise the 'normalcy' of an HIV-positive status. In almost every conversation with people living with HIV on treatment, the phrase 'there are many in the same situation in this community' was uttered. Grandmothers carefully guided children to focus the future, watched them 'to know their psychology', gave them extra love and attention, and normalised HIV.

What made psychological support difficult for grandmothers is that most grandmothers themselves were uncertain about the future of their grandchildren. Periods of ill health brought to the fore fears about the prognosis of the child. Most grandmothers experienced life before ART and had cared for and lost many relatives with HIV/AIDS. Having seen that patients on ART might die suddenly, many grandmothers shared a deep-rooted sense that living with chronic HIV is also precarious.

'Expert care', then, is comprised of close monitoring, the watching/observation of weight gain and strength, and attention to the emotional needs of adolescents; and embedding knowledge obtained from the clinic and Kwa Wazee within normal grandmother care. Central to providing expert care, however, was the *ability* of grandmothers to provide this care. The degree to which this was possible was related to being older – having less energy or physical problems – financial resources, and a grandmother's social position in the broader family, and whether family members supported her efforts.

Discussion: the sociality of expert care

Two forms of monitoring converge in the provision of expert care by grandmothers: monitoring as surveillance and monitoring as attunement to a constantly fluctuating body. But there is another layer of monitoring that often goes unnoticed, one that moves beyond the body to the social domain. While in anthropological literature the importance of the therapy management group in medical decision-making in sub-Saharan Africa (Janzen 1978) has long been established, too often treatment and care policies implicitly address patients and their direct caregivers in isolation from their broader social context (Dlamini-Simelane and Moyer 2016). This article demonstrates that the *social* position of both grandmothers and grandchildren in the kinship network influenced the ability of grandmothers to monitor the health and well-being of the grandchildren living with HIV in their care.

Owning your own kitchen: grandmother's decision-making power

Social relations were important in understanding the broader networks of grandmothers and whom they could draw upon or not to provide expert care. These networks included kin, such as remaining children and siblings, and peer networks and support groups, such as those at the Kwa Wazee organisation. The latter were of particular importance in solving intergenerational conflicts and noticing signs of bereavement with orphaned grandchildren. Kin networks were more complex.

Of paramount importance in providing expert care was decision-making ability within the household, or as Rosa said: 'owning a kitchen'. This turn of phrase not only related to who controlled what was cooked but also to the symbolic meaning of the kitchen as the 'heart of the house' (Weiss 1996). By saying she does not own a kitchen, Rosa is saying that while she monitors her granddaughter, she cannot decide how to feed her, pace her work or make sure she is accepted in the household. Rosa navigated these dynamics by using her income to make sure Agneta could buy something to eat, but was otherwise constrained by her social situation. Two of the other three grandmothers featuring in the vignettes were household heads; their main challenge was to divide up resources among household members who needed support. Strategies to avert jealousy included open discussion about the extra needs of their grandchild living with HIV. These dynamics show that access to resources is not just about materiality but also about less tangible factors, such as competing needs in a context of meagre resources.

In these dynamics, gender and kinship ideology are central. In Kagera, expectations of care and alliances to the 'natal home' are shaped by the ideal of the patrilineal family (see Block 2016). Brothers live on adjacent plots of inherited *shamba* (cultivated land), next to their natal home where their elderly parents live, accompanied by young and adolescent grandchildren for general support and company. Widows are supposed to be financially supported by their adult sons and deceased husband's brothers. In cases of divorce, very common in the area, women move back to their natal homes to be supported by their father or brothers (Kaijage 1997). Ideology and traditional family structures notwithstanding, kin-based care is highly uncertain in practice (see also Block 2014): grandmothers, people living with HIV and orphaned grandchildren find that 'the family' is more often than not a space for intense conflict, social isolation and even neglect, where only particular people can be trusted. The actual practice of merging clinic advice with values of grandmother care, such as making sure grandchildren are satiated and included, is contingent on the personal family histories of grandmothers that shape decision-making 'in the kitchen'.

Expert care as ensuring social belonging: grandchildren's access to land

While monitoring physical progress in terms of weight and physical ability to socially participate is about grandmothers' ability to successfully navigate power dynamics in patrilineal and virilocal kinship networks, well-being and social belonging are also related to grandmother's and grandchildren's social position in the kinship network. Children in Kagera are seen as an extension of their parents (see Whyte and Whyte 2004). The deceased parent also may have a history in the broader extended family, such as Agneta's mother whose 'many husbands' shaped the family's attitude towards her and extended to her daughter. Most importantly, however, deceased parents were present in discussions on grandchildren's access to land.

Land, the source of staple food and income and social connectedness in Kagera, was often a source of contention. Quarrels over who might inherit land and cases of land grabbing abounded, not just because land represents monetary value but also because – given that land in Kagera is inherited in the patrilineal line – it is a means of belonging and a means to establish a home and start married life for male grandchildren. Land is acquired through the paternal line. In three of the six cases analysed in this article, the person providing expert care was the maternal grandmother. Social exclusion was mostly linked to relatives' fear of the economic burden of chronic illness in resource-strained kin networks, especially when the grandchildren were taken care of by maternal relatives. Grandmothers carefully balanced their grandchildren's position in the household by ensuring grandchildren were well enough to not have a 'sick role' (McGrath et al. 2014) and did 'normal' household duties.

Expert care was geared towards creating social belonging in the family and everyday life. All three adolescent grandchildren were confronted by social isolation, at school and in the household. Social belonging at school and in the community was achieved by trying to fix bodily markers of HIV such as skin rashes, and social belonging in the family was about navigating matri and patrilineal networks of belonging. The biomarker of strength and weight was just as much about physical progress as it was about overcoming a 'sick role' (McGrath et al. 2014), ensuring participation in the household and orientating grandchildren to the future, and away from illness as a defining identity.

Conclusion

With increasing funding shortages and major existing gaps in the Tanzanian AIDS response, the decentralisation of care and the responsibility of the family will only be emphasised more. In this context, which is comparable to many other countries hit hard by HIV, it is of paramount importance to understand the roles of family caregivers in the surveillance of treatment, to understand what this 'expert care' entails, and to identify what constricts or enables such caregiving.

In providing expert care, grandmothers merge clinic advice and NGO advice with generational expertise and values to work towards inclusion and belonging. In doing so they walk a fine line between treating a grandchild as any other and paying special attention to the grandchild's needs, with the main aim of maintaining a child's social embeddedness. Care is about making sure grandchildren living with HIV are not isolated in the house: they must be strong enough to fulfil their kinship roles as grandchildren, go to school and engage in 'normal' activities. But care is also about providing them with extra love and physical closeness as a compensation for loss, and by wordlessly observing their health. These two forms of expertise become entangled when biomarkers such as weight and CD4 count merge with less measurable – but nonetheless bodily – markers such as 'ability to work', or 'smooth skin'. Clinic measurements are compared with physical strength, food advice is integrated with notions of satiation, and adherence becomes entwined with physical closeness and an intimate special relationship. Care then is not about individual responsibility; it is deeply embedded in social and family networks (Meinert 2013; Moyer 2014; De Klerk and Moyer 2017).

Biomarkers are not only indicators of good self-care and adherence but also of the ability of caregivers to navigate power relations in the family. This subtle sociality of care

is often lost in adherence seminars and treatment policy. By situating grandmothers as caregivers for grandchildren living with HIV in a broader family and social context, this article makes a plea for recognising the social ability of both patients and caregivers to not only provide expert care but also to engage in the self-care regimens often demanded by AIDS treatment programmes. The tendency to treat patients as autonomous individuals capable of making treatment decisions obscures how much of what shapes practices of care relates to patients' embeddedness in kinship networks. Given the likely further delegation of care to the family in Tanzania, awareness of how family dynamics shape the ability to care is crucial.

Note

1. While grandfathers also provide care to grandchildren living with HIV, their care roles are different; grandfathers usually provide material support. That said, there were cases in which widowed men took up all care roles for children and decided against remarrying, in order to prevent social isolation of (grand)children.

Ethical approval

This study is a follow-up of a PhD project on older caregivers and HIV for which approval was obtained from the Tanzanian Commission for Science and Technology (COSTECH). Further written approval was subsequently obtained from the local organization through which the follow-up was conducted. Each participant was provided with extensive oral explanation of the study and its objectives before asked for consent. subsequently explained taken through an oral consent procedure. Confidentiality was maintained at all times.

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