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“A Body Like a Baby”: Social Self-Care among Older People with Chronic HIV in Mombasa

Josien de Klerk^a and Eileen Moyer^b

^aFaculty of Governance and Global Affairs, Leiden University College, The Hague, The Netherlands; ^bFaculty of Social and Behavioural Sciences, Department of Anthropology, University of Amsterdam, Amsterdam, The Netherlands

ABSTRACT

As part of the chronic disease paradigm now widely used for HIV in sub-Saharan Africa, antiretroviral treatment programs emphasize self-care. In the informal settlements of Mombasa, Kenya, the management of stress—associated with economic precariousness—plays a significant role in self-care practices and ideologies. Based on ethnographic fieldwork, we examine how local narratives of stress and self-care intertwine with social responsibilities of older HIV-positive people. For older Mombassans, living with ‘chronic’ HIV means living with an unpredictable body, which affects how they are able to care for their kin. The physical reality of living with HIV thus shapes relational networks, making self-care a social practice. While, for some self-care entails managing the body so that its needs are hidden from loved ones, a kind of ‘protective secrecy,’ others enlist the support of their children and grandchildren in managing their body, and in that process subtly redefine generational expectations and responsibilities.

KEYWORDS

Aging; chronic illness; HIV/AIDS; Kenya; self-care; stress

It is very important to endure stress, so it does not affect your mind. You have to be able to use your mind, and if you get some sleep when confronted with stress, you are grateful. ... Lacking money is what causes stress—it makes someone die before their time. ... The work that is done by youth is impossible for us to do. ... It is not discrimination [being denied work because of having HIV], but old age.

Talking was Jonathan, a 56-year-old HIV-positive man, living in Bangladesh, an informal settlement on the outskirts of Mombasa, Kenya. When he and I (de Klerk)¹ spoke, he had been living with HIV for 25 years and had been on treatment for five years. Stress was a core theme in our conversations, as it was in conversations with other older HIV-positive interlocutors. The loose label of ‘stress,’ as configured in this multilingual community, conveyed a general feeling of anxiety about coping with everyday life with HIV and especially an unease about the unpredictability of the aging and chronically ill body. Stress was explicitly linked to the social lives of HIV-positive older people.

‘Stress’ in this article refers to being bound up in too many thoughts, often about the chronic conditions of everyday life and the health dangers thereof. While the English word ‘stress’ was often used, the Kiswahili terms *fikra* [contemplations/thoughts] and *mawazo*, a term that can mean worries, concerns, and ideas, depending on the context, were alternately used. The multivalent discourse of stress amongst patients was strongly linked to particular notions of ‘self-care’ that emerged from the Community Based Home Care response of the Catholic Archdiocese of Mombasa (henceforth ‘the CBHC program’) that, in this locality, started in 1996.

Already before antiretroviral treatment commenced, HIV-patients involved in home-based care programs in Eastern Africa were socialized into self-care by taking prophylactic medications, eating specific foods, and being encouraged to adopt a particular mental attitude, with the aim to survive as long as possible. With the advent of treatment these messages subtly changed into how to live on

CONTACT Josien de Klerk, PhD ✉ J.de.klerk@luc.leidenuniv.nl 📧 Faculty of Governance and Global Affairs, Leiden University College, P.O. Box 13228, 2501 EE, The Hague, The Netherlands.

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treatment and how to live life as well as possible. At the same time, new ways of relating to biomedical ‘scientific’ knowledge entered everyday social life (see Prince 2014). Particular ‘biomarkers’ to measure progress—such as weight and CD4 count—were used in clinical encounters; this focus on the biological body introduced new concepts, such as ‘immunity’ (see also Martin 1994). Decreasing CD4 counts were used to warn patients about the effects of stress on their health, thereby connecting the social and the physical in new ways.

These developments have been the subject of research into living with ‘chronic illness’ in sub-Saharan Africa, and the extent to which the chronic illness paradigm, focusing on long-term survival and normalization, holds true among specific groups of patients and in resource-poor settings, where a ‘crisis mentality’ might more accurately reflect the experience of living long-term with HIV (McGrath et al. 2014; Colvin 2011; Livingston 2004; Swendeman, Ingram, and Rotheram-Borus 2009; Seeley and Russell 2010).

In this article we focus on one specific group of patients: HIV-positive middle-aged and older people (aged 50 years and older) who live in informal settlements in Mombasa. We discuss the narrative of stress among this group, and how it bridges biomedical and social conceptualizations of the aging and ill body. We argue that the complexity of this notion of stress gives rise to a practice of self-care that is deeply embedded in the fluctuating corporeal experience of aging with HIV, and reflects the generational responsibilities of older people living in a precarious urban environment. These generational responsibilities make self-care explicitly social.

Self-care, chronicity, and the body’s physical ability

With the roll-out of antiretroviral treatment programs in sub-Saharan Africa since 2004, a chronic illness model focused on ‘self-care’ (Swendeman et al. 2009) implicitly structured public health projects in creating responsible adherent patients, meaning well-informed, empowered citizens, although practice often differed from this ideal (Mattes 2011). Early studies of these responsabilization projects showed that patients in situations of unequal access to medication learned to speak the language of treatment programs in ways that also fit with local moral economies, as ‘therapeutic citizens’ (Nguyen 2010). Later studies in settings of routine access to antiretroviral medication showed the range of ways in which patients take up or reject treatment program ideologies (Mattes 2011; Niehaus 2014).

Authors who describe people living with ‘chronic’ HIV in resource-constrained circumstances often compare different notions of ‘chronic’ in developed and developing settings. These authors point out that HIV has always been framed as a long-term condition (before and after treatment), and treatment does not necessarily take away the ‘acuteness’ of living with HIV (Livingston 2004; Kendall and Hill 2010; McGrath 2014). Others, critiquing the association of long-term biomedical management implicit in chronic illness models, have looked at the limitations of the health care system to provide long-term care (Colvin 2011; Russell, Seeley, and Whiteside 2010), including in situations where biomedical care is strongly oriented toward improvisation (Livingston 2012). The most important critique of the idea of regaining a normal life points to the many difficulties of managing chronic illness: food scarcity, the hunger created by taking antiretroviral medications, continued stigma and discrimination, and the everyday struggles of poverty. All of these factors influence whether or not patients adhere to treatment protocols, and make clear that adherence is never just physical but is also deeply social (Kalofonos 2010; Mattes 2011; Russell et al. 2010; Prince 2012; Moyer and Hardon 2014).

McGrath and colleagues suggest everyday life with HIV may be more appropriately conceptualized as a social space between the patient role and normal (healthy) life, shaped by everyday economic struggles and uncertainty (2014:314–315). This is true in particular for middle-aged and older people who, in sub-Saharan Africa, are often both caregivers and patients who need to engage in self-care (Ssengonzi 2007; Scholten et al. 2011; Wright et al. 2012; Schatz and Gilbert 2012). The psychosocial well-being of older caregivers is related to structural poverty, increased care

responsibilities, medical problems, the loss of strength in old age, grief and mourning over the loss of loved ones, and lack of support (Oburu and Palmerus 2003; Seeley et al. 2009; Wright et al. 2012). For older people living with HIV in Mombasa, the ‘stress of everyday life’ (Le Marcis and Ebrahim-Vally 2005; see also Manderson and Smith-Morris 2010; Prince 2012; Whyte 2014; Mattes 2014) is mainly felt in relation to bodily ability.

Attending to the embodied experience of HIV and its management provides an alternative framing of chronic illness management, which follows McGrath’s and colleagues’ articulation of chronic HIV as a new ‘social space’ (2014). The unpredictable body takes center stage in this new social space. In the process of responding to the constantly fluctuating condition of the body, Mol’s notion of ‘tinkering’ (2008) seems apt. With respect to chronic illness, ‘care’ is a fine process of attuning to the body, one in which not only patients and health staff but also family members are engaged. In the era of routine treatment, self-care moves more and more out of the hospital and into the home. Meinert conceptualized self-care in this era as a ‘regime of homework,’ whereby health authorities assign care-work to patients and their families, and expect them to carry it out in their home context (2014:119–120). This raises the question of what exactly ‘self-care’ is in these contexts. Recognizing the home as the locus for self-care invites us to think about self-care as relational, something happening between the patient and others in a home, where the ‘attuning’ to the fluctuating body takes place on an everyday basis. ‘Self-care’ does not occur in a vacuum; it is embedded in personal and family biographies (Dilger 2008; Henderson 2011; de Klerk 2011). Nor is it confined to body management; it extends into a person’s relational responsibilities.

In the next sections we first discuss the CBHC program and its way of constructing the management of everyday life in relation to maintaining health. We then focus on how everyday life and clinic messages translate into experiences of living with an aging, ailing body in everyday life at home. Finally we explore the way older HIV-positive patients incorporate their ‘new’ in-between physical states into their life at home and explore how practices of self-care are grounded in these lived experiences.

Background: The community-based home care program

The oldest community-based response to HIV/AIDS in Mombasa is the Catholic CBHC program, which has been running since 1996 and which began providing antiretroviral medications in 2002. In 2012 the CBHC program provided antiretroviral therapy to approximately 3000 adults and 1300 children in the informal settlements of the West Coast region, of which Bangladesh is the largest, and in the rural North Coast. The program is funded by PEPFAR.²

Many CBHC staff, especially counselors, have been affiliated with the program since its inception. The majority of the counselors had previously been community health workers, and some were themselves HIV-positive. Before the introduction of antiretroviral treatment and the launching of numerous counseling and training programs through the Kenyan National AIDS Control program (NASCO), which was founded in the late 1990s, CBHC programs referred counselors to specific training programs, making it possible to trace the genealogy of ideas around counseling (Simbaya and Moyer 2013). Several of the first generation of CBHC counselors were trained in Tanzania; more recently they have been trained through NASCO.

From its inception, the Catholic CBHC program involved family members in care provision, thereby responding to the many patients that were found bedridden and abandoned, unable to eat, and neglected by their families. Self-care, then, was always cast in social terms and never as just an individual responsibility. In the pretreatment era, community health workers went to the homes of the sick and talked with them, provided locally made porridge (*unimix*) and multivitamins, treated opportunistic infections,³ and supported patients to continuously take their drugs. The introduction of antiretroviral treatment was a combination of activism and chance, and was related to the personal convictions of one of the founders of the CBHC program, Sr. Pauline. She was the only nongovernmental representative from Kenya to be trained in the first PEPFAR training session in

the United States before free drugs were officially rolled out countrywide in 2005. These genealogies and personal histories framed the further development of the treatment and care program in Mombasa; the program both followed the general guidelines set out by NASCOP and was embedded in a broader history of care and community mobilization around HIV.

The proportion of people older than 50 years in the total patient population is slowly increasing. Data from the Mikindani clinic, one of the major clinics in the program, indicate that the total number of patients enrolled in the program more than tripled between 2006 and 2012, and that the ratio of people older than 50 years living with HIV almost doubled from 6% in 2006 to 11% in 2012.⁴ To cater to this population, an older people's support group was started, although it was said that many older people found it difficult to attend physically.

Methods

In this article we draw on ethnographic research conducted in the spring of 2012 in Mombasa. The research for this study took place primarily in the informal settlement of Bangladesh, located near the harbor on the outskirts of town, although a private HIV support group in the eastern part of town and several CBHC clinics located in other informal settlements around the port were also visited. In all of these settings, the lead author (de Klerk) conducted observations, semi-structured interviews and group discussions with older HIV-positive people, and interviews with staff from the treatment programs. The main ethnographic data were collected through repeated biographical interviews and spending time with people older than 50 years and members of their families, leading to a total of 38 in-depth interviews and observations with eight older people and some of their family members. All but one were members of the CBHC program and a local HIV support group, which was led by a community-based organization, Bamako, but was affiliated with the CBHC program.

Most of the older inhabitants of Bangladesh had migrated from Western Kenya to Mombasa, a major port city, in search of employment with the many companies in the Export Trading Zone (EPZ). The men sought work as security guards or casual laborers in the harbor, while women searched for day work in the informal economy. Many of these older people lived in nuclear family structures with their adolescent children, while their extended families remained in rural areas. Most of the 'older' patients enrolled in the CBHC program were between 50 and 60 years; only two of my eight main interlocutors were in their late 60s.

All interviews were conducted and transcribed in Kiswahili. Different approaches were employed to talk about self-care. To talk about practices, the phrase *kujitunza mwili wako* [to care for your body] was used, to talk about body management *kuangalia mwili wako* [to look after your body] was used, and to talk about self-care messages from the clinic people were asked what they had been told about *kulinda* [guarding the body] and *kujilinda* [guarding themselves].

The arguments presented in this article draw on all of the interviews and observations, the situations of two older people are foregrounded, in particular, Emily (50) and Jonathan (56). Emily had been on treatment for nine years; she lived with her HIV-positive husband (60) and their adolescent children. Jonathan, a widower and father of six adolescent children, had been living with HIV for 25 years and had been on treatment for five years. Their stories raise distinct issues around body management and the incorporation of 'regimes of self-care,' patterns that emerged from the broader body of data. They also show how such regimes are embedded in personal biographies.

When saying "don't stress" is a form of care

We talk about stress. And then I ask them, "So if you have stress yourselves ... how can you feel good, how should you live? If you have a lot of stress, you can get many illnesses, so you won't feel well ... you will be coming down and down" [deteriorating in health]. ... Stress can bring many illnesses, thoughts, ulcers, [high

blood] pressure because of stress—you will be weak, your weight can drop, so you have to [say] that “if I will accept this I can live well, without many thoughts.”

‘Stress’ came up in almost every conversation with patients and health staff. Mary, one of the counselors of the CBHC program, and I were sitting in one of the counseling rooms of Mikindani clinic. Mary explained that the precariousness of livelihoods and conflicts in social relationships can both cause stress. In her counseling she tried to refocus patients, to show them possibilities:

Some patients come and say: “I do not have food. I have nothing to assist me, I started to use drugs but I do not have food, I do not have a place to sleep.” I tell them: “It is good you get the drugs, they will assist you. In the past you had to buy the drugs—they were very expensive, you would not have been able to afford them your entire life. Thankfully you now get these drugs [for free]. You can start a small business, cook potatoes, cook *chapati* [fried pancakes], with which you can get a little money to buy something to eat, to buy porridge. We also provide porridge flour, so if you have absolutely nothing you tell the doctor and they can assist you with porridge flour, and you eat porridge and use your medicines, and then you slowly return to your strength and can find your own way, even if it is washing clothes for others.”

Counselors like Mary did not make light of patients’ problems; instead, in this form of care health staff tried to support patients to navigate the conditions in which they found themselves. Although not said explicitly in the above quote, the message not to stress was part of a local discourse of enduring adversity.

I often observed counselors using terms that had traveled to East Africa with global AIDS activism, which they acquired in their various trainings. One was ‘living positively,’ meaning to be accepting of one’s HIV status, to not be affected by adverse thoughts, and to engage in a range of practices, both physical but especially psychological, aimed at survival (Levy and Storeng 2007). Originally modeled on support groups’ philosophies in Europe and the United States and resulting from the stigma related to the associations between AIDS and imminent death, the notion of living positively was taken up, interpreted, and transformed within particular HIV/AIDS care and support programs into advice that mapped onto local circumstances and values of care within the CBHC program, which had been at work for a decade before the introduction of PEPFAR-funded treatment. These included notions of peaceful co-existence in families and family responsibility that were rooted in the program’s history as a palliative care program, fighting discrimination and the abandonment of patients by family. Social exclusion of patients still prevailed, and especially for older people because of the association of HIV with improper sexuality. Moreover, despite the availability of treatment, HIV was still associated with a possible sudden death, not with long-term survival. Many patients discussed conflicts at home, problems with negotiating sexual relationships, and their inability to find work and food with their counselors and were advised on how to navigate relational issues. These concerns and the particular tensions in relations of family care featured in how counselors conceptualized ‘living positively’ in this locality.

Antiretroviral treatment requires strict bodily regimes, which patients call *masharti* [the rules]; these include taking medicine at a specific time each day, eating nutritious food regularly, giving up alcohol, having protected sex, seeking medical care in case of illnesses, visiting the clinic each month, and reducing stress. In this sense the switch from palliative care to a treatment program emphasized, to an extent, a notion of individual responsibility for self-care, for example, in urging patients to involve others and maintain good relations, rather than the earlier days of urging the family to take up the work of caring for the patient.

In counseling encounters the personal background of the health worker was central. On the one hand they could serve as an extension of the ‘care collective,’ helping translate the *masharti* into realities that worked for patients; on the other hand, especially when they themselves were HIV-positive and had found a new source of identity in their roles as educators, it could be difficult to respect and accept alternative views from patients. No matter the amount of translation, being on treatment came with socialization into particular ‘regimes’ of self-care.

The regimes of self-care promoted by the clinic were merged with existing knowledge about the body, health, and illness. Many of the older HIV-positive people who were members of the treatment program in 2012 had been living with HIV for a long time; they were in a way ‘the survivors’ (Whyte 2014) of the pre-treatment era. To survive they had devised a regime of self-care themselves, a set of practices that entailed surrendering to the rhythm of the body. Often HIV was not the only ailment; older people sometimes had other chronic illnesses such as diabetes, high blood pressure, or other conditions and disabilities. These sometimes were foregrounded, depending on a particular social situation, as in the case of an older man who complained about the different treatment standards between diabetes and HIV in the public facility.⁵ But at other times, noncommunicable diseases, HIV, and other diseases, became conflated in the unpredictable body. All of the older HIV-positive people had changed their work and daily activities to match their bodies’ strength, and built in strategies to be able to rest their bodies regularly and follow the fluctuations of the body.

Aging, the unpredictable body, stress, and self-care

A central theme in the biographical stories of people aging with HIV concerned the body’s unpredictability and the consequences this had for social relations. Building on literature that sees the body as vehicle through which the world is experienced—including through the social reactions its appearance elicits (Whyte 2014)—we emphasize the body’s physical ability as a central factor that shapes a person’s social relations. Through Jonathan and Emily’s stories we show that while Jonathan’s ‘body work’ takes center stage in his social relations, Emily’s ensures its invisibility in social relations.

The stress of aging with HIV: Jonathan

There is a difference between enduring and relaxing. When I endure I accept that there is something that presses me down and I just endure it. When I relax I take those thoughts from the mind completely. The first thing is to endure. ... [Like] I have done my calculations, I know there is no way, today is the 30th of April and the landlord wants 9000 shillings [106 USD in 2012], because I still owe him three month’s rent. But there is no place to get that money. So then, after contemplating, I relax. If he wants to chase me out, he will. Or maybe when we talk he will allow me to stay.

Life in the informal settlement was expensive. Unless one owned a house, monthly expenses included rent, water, food, secondary school fees and other expenses, such as extra tuition and school necessities. Food requirements that accompanied antiretroviral treatment, such as eating several times a day, were often not met. Physically, older men and women living with HIV could often not compete with the many young strong men and women who flooded the city in search of work; many of the older people now on treatment had been near death before starting to take antiretroviral medication. The dual social and financial responsibilities—as parents of adolescent and young adult children, and as children of parents in advanced old age—that came with this life phase added to concerns about the body’s physical ability.

This was the case in Jonathan’s life. Before starting treatment in 2007, he had been living with HIV for 20 years. He found out his status through donating blood to a friend in 1987. Thinking he would die within six months he started drinking heavily, but a chance encounter with an Indian doctor who offered to treat him and teach him about long-term survival changed his outlook on life. Weekly vitamin boosters and careful dieting helped him survive. Two bouts of tuberculosis in 1998 and 2000 almost killed him, but he was able to survive until antiretroviral treatment became available, and even then a little longer, as he only started treatment after his wife died of AIDS. Confiding in her was, he felt, not possible: scared of her probable anger, he kept his status a secret while she was alive, but he did test his children, who were found to be negative.

After his wife passed away, Jonathan became a peer counselor in the CBHC program. His strong dislike of the secrecy and the stress he felt in his tempestuous first marriage, in combination with

clinic and support group rhetoric on avoiding social conflict that might lead to stress, shaped his second marriage to Gloria, also HIV positive and a peer counselor. Jonathan only entered into marriage with her after a mutual agreement to live stress-free, to mutually support each other, and to not fight.

A long history of ill-health and the knowledge Jonathan acquired through his doctor had fine-tuned his awareness of his body, to which he added the knowledge on self-care he acquired at the clinic and in support groups. As chairman of the support group and peer counselor for the treatment program, Jonathan had become well versed in the technicalities of his immune system. He used his CD4 count to comment on his daily life and was particularly concerned about stress:

I knew that of course my CD4 was very low. I was struggling with many things, and I received the report that my mother was ill, and I saw my life and the way it had changed and I thought of home, and I thought of here, and I thought again of the way my family stays. So all those things I put in my mind, and I saw that I am one person, I am alone, and my family there [at his natal home in Western Kenya] has at least eight people and all depend on me, and ... I do not have money. ... It mattered a lot to me: my mother, she is there, I have to bring her something to assist her. I was thinking of my mother—of course if the person that is close to you is dying, your CD4 drops.

Jonathan sees a relation between his body's physical state and his financial situation, which included having to pay for rent, food, and secondary school costs for three children. Being older meant that Jonathan could not find work easily, and his life was marked with recurrent episodes of financial crisis. For some obligations he found short-term solutions: buying food on credit, paying the tuition in installments. But his rent was too large a sum and two weeks after I met him, Jonathan was evicted from his home. He and his entire family moved in with one of the other older members of the support group.

Jonathan made direct links between the stress of everyday survival and his CD4 count: "Last [time] I checked it was 192 and Gloria's [his wife] was 254. She dropped so much, she was 450 or something. Sometimes we go without food, we rely on food assistance." He used his CD4 count to check his body's progress and to comment on everyday struggles in the informal settlement (see also Marsland 2012). In this sense he embodied what Martin (1994) predicted as a new phase in the interaction between popular concepts of the immune system and the scientific techniques to monitor it. Increasingly patients incorporate biomarkers such as weight, CD4 count, and viral load into their everyday narratives of progress (see Whyte 2014). In December 2011 Jonathan's elderly mother, who had been sending him regular food supplies and taking care of two of his children, became ill, and Jonathan said he felt his CD4 count decreasing because he was thinking too much. His stress sometimes was so bad that he was afraid he might be run over by a lorry, just because of thinking so much:

Stress lowers CD4 because when you are thinking a lot, you also spend little time eating. Someone with stress eats very little, even [when he has] tea, [he] only [drinks] one cup, he might have something [to eat] with the tea but feels the mouth becoming heavy. ... You can have money [to buy food] but the stress takes over and you fail to eat, because this issue in your heart is paining you. Stress brings pain in your heart, so even when you are brought food, you do not eat; after eating those issues bother you, because those issues are in your head. ... But when there is someone close to you, they can tell you, "let go of those issues and let's eat," and then you are able to eat.

Equally so, when his CD4 count rose, he felt this in his body's requests for large amounts of food and the return of strength and spirit.

For Jonathan, stress was related to the unpredictability of his body and its declined ability to engage in income-generating activities in an environment where physical strength is the main capital for survival. After being dismissed from the large tea exporting company where he worked, Jonathan gave up on finding a paid job. He started going to AIDS awareness seminars on a monthly basis, using the 'sitting fee' and transport money as a source of income. But in recent years, changes in donor support for antiretroviral programs had decreased such payments (see also Moyer and Igonya 2014). Sharing his worries with family and in the support group had helped him combat despondent thoughts.

Embodied stress: Emily

My health is not good, just like I told you before, my health just—my health is not good. The medicines only give strength. ... As far as the skin I have, the skin has also changed already. I used to be brown. ... And old age has commenced ... I can only sleep a little. At times I feel my head, at times I feel my stomach, at times I feel my chest, you know, it just brings different ailments in your body. At other times I do not feel like getting up, occasionally you feel malaria, so you just feel like a child, I mean like a baby, the same as you have a baby right now [here Emily refers to my ten-month-old daughter]. It wants just—every hour you need to look after it, every hour.

Corporeal experiences of aging with HIV differed within the broader group of older people I spoke with in Bangladesh. Some maintained a high CD4 count for years, and did not need to start antiretroviral treatment. Some responded extremely well to treatment and completely regained their health, yet others barely saw any improvement. Despite these physical differences, all of them shared Emily's experience of living with a body "like a baby." Physical challenges included difficulty walking (and hence finding work), the co-existence of other (chronic) illnesses, and psychological problems, such as bouts of despondency that led to isolation and loss of appetite.

Emily experienced her body as needing constant care and attention. AIDS changed her appearance: she became darker skinned and thinner, and she was convinced that these physical signs were being 'read' by neighbors. She developed an ulcer that she attributed to the stress of being ill. Because of this she could only eat small amounts of food at a time, which affected her ability to gain weight. But whenever she failed to eat, she had dizzy spells. Her eyes had been affected, whether by AIDS, the medicines, or old age, she did not know; in any event, she could no longer read properly. Attending Sunday church services was a challenge; fasting and praying the entire day was almost impossible on medication. She also felt constrained in her movements: the 24-hour bus journey to visit her elderly mother was arduous, as the bus only stopped at certain hours and interfered with her self-care regimen. She was also suffering from a prolapsed uterus, but refused the necessary surgery; the risks of dying and abandoning her children were larger than her pain and discomfort.

Emily discovered her HIV status when her fourth child, a daughter, kept on falling ill and eventually died. After her daughter's death she went for an HIV test and was found to be positive. Her husband also tested positive. After a few rocky months they decided to stay together. The corporeal experiences of aging with HIV—the unpredictability of their bodies—has shaped their daily routine. Emily's husband, who was 60 in 2012, could not find employment anymore. He left the house every day before 6:00 a.m. to look for day jobs in the harbor. Emily used to be a hairdresser but the long hours of standing made her decide to start buying vegetables from the main market in town and to resell them from her home. This involved getting up at 5:00 a.m. so she could reach the market early. Although navigating the chaos of the market and the public transport, and carrying a 30 kg bag of produce, was exhausting, she was able to rest her body after 9:00 a.m., which is when she took her medication and felt her strength returning. For the rest of the day, she merely did housework, took care of the chickens, cut cabbage for resale, and attended to customers, and whenever she felt tired she could sit on the sofa.

Emily also managed her body in front of her dependents. She made sure her children never saw her in bed, as their memories of her being very ill and confined to bed were too fresh, even after nine years of being on medication. Emily was concerned about the effects of despondent thoughts on her body's strength and fiercely tried to keep busy at all times:

Aaah, thoughts, thoughts. I feel my heart is very tired. ... My heart feels tired and also my bones, I feel they are tired. ... Thoughts are bad, they bring illnesses to your body. You think that you are ill and then there is nothing, when you go to the doctor to be tested, you are told there is no illness, it is the thinking, and furthermore, it brings ulcers.

Stomach pain and lack of appetite indicated to her an increase of stress. To keep her body strong for the sake of her children, she fought back against thoughts and worries by singing and dancing to the radio in her room.

In contrast to Jonathan, Emily was—like many other older people—not very interested in her CD4 count. She did not know its exact level: at one time the government treatment program of which she was a part checked her blood, but did not note the results; another time the machine was broken. She relied on her own knowledge of her body and the doctor's declaration that she was doing well. Emily mainly kept track of her body's progress through sensing whether she was losing or gaining weight. This physical marker of bodily well-being is rooted in the pre-treatment era, when loss of weight was one of the primary symptoms of HIV/AIDS. Self-care, as Emily's story shows, is not just about following clinic rules that make the body into an object to discipline. Instead, the lived body is central, and self-care is not an individual undertaking.

The sociality of self-care

Older HIV-positive people often linked their bodily well-being to the state of their social relations. This connection reflected both their social responsibilities and abilities to engage in self-care as well as clinic messages about avoiding stressful social relationships. In this section we first address how biomedical notions of health have become embedded in everyday self-care and secondly how practices of self-care shape social relationships.

Biomarkers and social relations

In this context, bodily well-being is contingent on social relations. Whyte's observation that patients relate their CD4 count not just to their body's progress but to their social and existential situations and that they use such numbers 'as relational agents in a life-world' (2014:232) is equally valid for practices of reading the body in Bangladesh. The interactions between health workers and patients in the CBHC program were marked by what Mol (2008) called the 'logic of care,' whereby health workers attuned, gently, empathetically to patients' personal backgrounds, acknowledging the often unexpected course of living with a chronic illness in the context of dire poverty. In counseling sessions, a declining CD4 count was explored by asking about potential stressors in a patient's life, and included explicit advice to avoid quarrelsome relationships. Patients were resocialized to evaluate not only their bodies but also their social relationships through biomarkers such as CD4 count and weight (see also Whyte 2014).

Older HIV-positive people related both stress and ways to overcome stress to the state of their relationships. A set of rapid interviews with older patients all pointed to the association between relational problems and the body's decline, with people linking decreased CD4 counts to quarrels in the house, worries over children with HIV, or concerns over being dependent on others to provide for children. Equally, stress-alleviation techniques focused on managing social relations in order to contribute to the health of the body. Stress-alleviation techniques included seeking the company of close relations who could ease worries or provide distraction from thoughts. Most revealing however were the ways older HIV-positive people actively shaped the social relations that were central in their self-care: forbidding children and other household members to quarrel in front of them, asking a daughter and grandchildren to move in for company, and negotiating the terms of partnerships. Not only are biomedical notions like CD4 counts and the immune system associated with the relational body but relationships themselves are reshaped according to biotechnical notions of health in the everyday practices of self-care.

Bodily regimes as well as living with the unpredictable body affected and involved patients' family members in various ways. Close family members were often involved in care, providing psychological support, encouragement, and distraction, and reminding patients to take medication. Being diagnosed with HIV, especially at an older age, in almost all cases meant a decrease in a person's social network and a change in degrees of closeness. All the social circle diagrams⁶ I drew with older HIV-positive people about the change in their social relationships indicated an almost complete loss of relationships of assistance at the time of severe illness except for one or

two people who remained close. After recovery these few remained close and others somehow reappeared but relations of trust were never completely re-established. This experience also influenced self-care practices.

Because others are involved in self-care, information about one's HIV status, the daily rhythm of physical and mental well-being, drug regimes, financial and other concerns, somehow need to be passed on to others. But how much information, to whom, and when to share it is part of an intricate process of 'knowledge management' (Whyte 2014) that considers the consequences of this information for patients' generational roles. Most older people living with HIV experienced that imparting such information subtly changed these roles. Secrecy was thus central to older people's self-care, and aimed at ensuring that they remained socially embedded (De Klerk 2012; Moyer 2012). We term this careful consideration of sharing knowledge about the body *protective secrecy*. Returning once more to Emily and Jonathan, we examine how various strategies of knowledge management maintain or redefine generational roles.

Protective secrecy

Practices of self-care were intrinsically related to questions about how to be a good mother or father, wife or husband, and daughter or son to an elderly parent while living with the illness. Gender shaped the way these generational roles were understood or reinterpreted and subsequently translated into self-care. For Emily her role as a mother entailed being a caretaker and provider for her children and this role was paramount. She explained that her children vigilantly monitor her health:

You know, they saw me ill all the time, especially my boy. ... As far as that boy is concerned ... when it reaches nine o'clock, and someone happens to distract me, that child will come and tell me: "Mama, you know, it has reached nine o'clock, come, take your medicine." Something that helps us is that in school they also teach the children these things about these medicines, so he sees that I also, that I also use medicine and therefore he is not afraid for me.

Protecting her children means that she sometimes chose to ignore the signs of her body or modified her response to her body's needs in accordance with her children's needs. She ate when her children were there to watch her eat, and she rested when her children were in school. Emily shaped her self-care in such a way that she did not allow her body to be very present. She first and foremost was a mother, providing for and protecting her children.

Jonathan's attitude to sharing information drastically changed during the course of his illness: he actively involved his adolescent and young adult children and his partner in his self-care. When he had to start treatment and needed a treatment buddy he disclosed his HIV status to his beloved ten-year-old daughter. Although initially shocked, she took up the task and became one of his main emotional and financial supporters, coaching him gently when he failed to eat when overcome with thoughts.

Whereas Emily's husband, also HIV-positive, is absent in her stories about self-care, Jonathan's wife plays a central role. She is portrayed as his confidante and helper. She cooks and washes and provides him with company and they share views:

I already knew her in 2006 and we started staying together in 2007. The only condition was that she told me her position on using [antiretroviral] drugs, whether she is taking them and which type. And another was that we would not have more kids, and if she wanted [children], only maybe after ten years or so because we don't have much food or money to bring them up. Because we know our status and [she is] also a counselor, we [agreed that we] will stay in such a way that no one will know we are HIV positive, and even if they do, it won't break our hearts or make us stop using antiretroviral medications.

Before starting treatment, when he was close to dying, Jonathan shared his status with his elderly mother, and returned to her rural home to die. He later deeply regretted that decision as his mother, having lost all her other children to HIV, was deeply distressed:

When an old woman sees you sick all the time it changes her thinking. ... Especially when ... [she] knows that you are the breadwinner and then [she] thinks that [her] child is dying. ... I was the only survivor. ... At that time my siblings had also died and their children had remained. And my uncle had also left her his children who had become like my siblings. ... She was grieving so badly, like the entire week her head was changed and I tried to tell her don't worry. So I left and stayed far away, so that even if I was ill, I could keep her happy. Even if I was confined to bed and she asked me "how are you doing?", I could tell her: "I am fine."

To protect his mother he decided to return to the harsher life in Mombasa where his mother could no longer see his bodily well-being.

Through his participation in the CBHC program, Jonathan gradually changed his definitions of what good fatherhood was and what a good partnership entailed. For him fatherhood was not necessarily about being a provider; it was about sharing and mutual advising. A partnership was no longer about raising children together but about confiding, mutual support, and stress-free living. Having redefined generational roles in this way made it logical for him to share his psychological distress, his treatment needs, and other elements of body management, and he believed that doing so contributed to boosting his immunity. But this choice also had a downside; while Jonathan saw the sharing of information as a core element of intimacy with partners and between parents and children, it also could be a burden for his loved ones.

The extent to which information on the body's progress and management is shared was dependent on specific generational relationships. In some intergenerational relations, the body became the center of attention; in other cases the body's needs were hidden against other relational concerns. While many older HIV-positive women in Bangladesh shared their self-care with the adult daughters, and older men did the same with their partners, both Emily and Jonathan talked about being protective towards elderly parents and young dependent children. Jonathan transgresses this boundary by confiding in his young daughter, and in doing so he redefines the role of fatherhood. While the scope of this study does not allow for broader claims to be made about how strategies of self-care redefine gendered and generational roles, further research into this issue amongst both HIV-positive fathers and mothers may help us better understand moralities of intergenerational family care.

Conclusion

In the era of routine treatment, the goal has become to live as normal a life as possible (Moyer and Hardon 2014), a life in which intimacy that enables mutuality, intersubjectivity, and life itself is essential (Le Marcis 2012). These lives are difficult to achieve, and often patients find themselves in states of permanent transition (Mattes 2014). New 'social spaces' emerge, filled with people who are neither ill nor back to normal life (McGrath et al. 2014). In this article we examined how this new social space shaped bodily care in the intimate domain of the nuclear family. The research shows how self-care practices—partly informed by treatment programs, partly by living in the precarious circumstances of the informal settlement—are shaped by gendered and generational responsibilities. Managing the HIV-positive body is also about being a good mother, a good father, a good partner, and a good son or daughter; it is about caring for 'the hidden collective', the people not present in the consulting room (Mol 2008:57; Marsland 2012:474). Through everyday enactments of self-care this hidden collective is made visible. While body management involves adhering to treatment and observing the rules, older people living with HIV focus more on building up the body's ability to fulfill social roles. They do so by continuously monitoring the body's ability to work, and its need to rest and to eat and go for treatment, and adjusting pace as needed. It is about making do with pain, fatigue, stress, weakness, and strength—of *feeling* HIV—in order to live and be mothers and fathers and partners and children. An expanding body of work on living with HIV on treatment and rebuilding lives aims to centralize the body by conceptualizing HIV-positive patients as 'embodied subjects'. HIV patients experience their bodies' limits and abilities in relation to their social relations (Livingston 2005; Henderson 2011; Whyte 2014). Self-care, then, is not just a 'regime of homework'

but also an embodied practice. In practicing self-care older HIV-positive patients adjust their body as well as possible to the demands of their positions as parents, as children of elderly parents, as partners, as patients. Health staff assist in this process.

As it is impossible to manage the structural conditions that produce stress, especially with an unpredictable body, patients are socialized to 'avoid' stress. More than just a biomedical route to good health, stress management messages in the CBHC program did not come from the 'outside,' but were already deeply embedded in the social realities of life in the informal settlement, just as are most of the staff members of the clinic. When someone says, "don't stress," it should be seen as a gentle form of care. Unable to change the structural circumstances of life in the informal settlement and the demands made on their bodies, older patients try to avoid stress by managing their relationships in particular ways, either actively involving others in their self-care or by protecting dependents from too much information. This sociality of self-care forms part of the morality of care that has emerged in the face of the new reality of living with chronic illness in precarious circumstances.

Notes

1. In this article, the use of "I" refers to the first author, Josien de Klerk, who collected the data used in this article and took the lead role in writing the article. Eileen Moyer was the PI on the overall study, assisted in the study design and provided key feedback during the analysis and writing phases.
2. The United States President's Emergency Plan for AIDS Relief.
3. Opportunistic infections are infections that often occur in people with suppressed immunity.
4. Deaths amongst the total patient population decreased from 20% to 13%, but the percent that were categorized as 'lost to follow-up' remained the same: around one-third of the registered patients were no longer actively attending the clinic.
5. In the CBHC the management of chronic co-morbidities were included in comprehensive care, but patients had to contribute a small fee.
6. I asked each informant to draw a circle, with the informant in the middle, and to place certain important people close or far away in terms of assistance, closeness, and friendship before becoming ill, and then indicate how their relative position changed in the time of severe illness and after recovery.

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Notes on contributors

Josien de Klerk is lecturer in Global Public Health at Leiden University College, The Netherlands. Her long-term fieldwork forms the basis of a critical analysis of the politics around aging and care in the treatment-dominated AIDS landscape in Eastern-Africa.

Eileen Moyer, PhD, is associate professor of urban and medical anthropology at the University of Amsterdam. She works on global health, gender-focused development initiatives and transformations in urban African masculinities in east and southern Africa.

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