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Understanding HIV-related stigma in older age in rural Malawi

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Abstract

The combination of HIV- and age-related stigma exacerbates prevalence of HIV infection and late diagnosis and initiation of anti-retroviral therapy among older populations (Heckman et al. 2002; Moore, 2012; Richards et al. 2013). Interventions to address these stigmas must be grounded in understanding of situated systems of beliefs about illness and older age. This study analyses constructions of HIV and older age that underpinned the stigmatisation of older adults with HIV in rural Balaka, Malawi. It draws on data from a series of in-depth interviews (N=135) with adults aged 50-~90 (N=43) in 2008-2010. Around 40% (n=18) of the sample had HIV.

Dominant understandings of HIV in Balaka pertained to the sexual transmission of the virus and poor prognosis of those infected. They intersected with understandings of ageing. Narratives about older age and HIV in older age both centred on the importance of having bodily, moral and social power to perform broadly-defined "work". Those who could not work were physically and socially excluded from the social world. This status, labelled as "child-like", was feared by all participants.

In participants' narratives, growing old involves a gradual decline in the power required to produce one's membership of the social world through work. HIV infection in old age is understood to accelerate this decline. Understandings of the sexual transmission of HIV, in older age, imply the absence of moral power and in turn, loss of social power. The prognosis of those with HIV, in older age, reflects and causes amplified loss of bodily power. In generating dependency, this loss of bodily power infantilises older care recipients and jeopardises their family's survival, resulting in further loss of social power. This age-and

HIV-related loss of power to produce social membership through work is the discrediting attribute at the heart of the stigmatisation of older people with HIV.

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Keywords

HIV; older age; stigma; Africa; Malawi; power; work

Research highlights

- Unique study of how HIV- and age-related stigmas are linked in an African setting
- Argues that both stigmas are grounded in understandings of power and production
- Unproductivity is the discrediting attribute underpinning layered HIV and age stigma

48 **Main text**

49 HIV-related stigma affects the physical and mental health of people living with the virus,
50 deters individuals from disclosing that they have HIV, may discourage treatment adherence
51 and limits uptake of HIV testing (Mahajan et al., 2008). It has been identified as a major
52 barrier to preventing new HIV infections, providing effective care for those already infected
53 and achieving the goal of ending the AIDS epidemic (UNAIDS, 2014). Considerable
54 progress has been made in understanding the nature and effects of HIV-related stigma among
55 younger adults (see review by Mbonu et al., 2009), but the same cannot be said for older
56 adults.

57 Understanding the representations through which stigma of older adults with HIV are
58 perpetuated is critical given high and increasing prevalence at older ages. In 2012 3.6 [3.2-
59 3.9] million adults aged over 49 years had HIV (UNAIDS, 2013). In high-income countries
60 with concentrated epidemics and longstanding access to antiretroviral therapy (ART), older
61 adults comprise almost a third of those with HIV (UNAIDS, 2013). Even in sub-Saharan
62 Africa's generalised epidemic, by 2007 when ART had been available for just a few years,
63 around one in seven adults with HIV were aged over 49 (Negin & Cumming, 2010). In
64 Malawi, it was one in five (18.6%) (*ibid.*).

65 Research about HIV-related stigma has not kept pace with the demographic realities of the
66 epidemic. It is unclear whether HIV in older age is considered more or less stigmatising than
67 in younger age or whether older adults with HIV are more or less able to resist and challenge
68 stigma than their younger counterparts (Emlet et al., 2015). Nevertheless it is widely
69 anticipated that HIV-related stigma is produced about, and experienced by, older and younger
70 adults differently.

In Goffman's seminal work health-related stigma is characterised as an "attribute that is deeply discrediting", arising within social relations and disqualifying those with the attribute from full membership within the social group (Goffman, 1963:3). Older adults with HIV/AIDS are expected to face a "double jeopardy" (Emlet, 2006:781) of stigma related to negative attributes a given social group associates with both old age (e.g. with regard to sexuality or dependency) and HIV. Research in high-income settings established that these negative associations can act in concert to produced compounded or layered stigma (*ibid.*).

Limited evidence available from sub-Saharan Africa confirms that some older adults with HIV anticipate both HIV- and age-related stigma. A study in Togo found that fear of gossip, stigma and discrimination prevented more than a third of older participants from disclosing their HIV serostatus (Moore, 2012). Two studies in Uganda suggest that age- and HIV-related stigma might be mutually reinforcing, shaped by the interplay between perceptions of HIV generally and the social and economic processes that underlie broader age-related inequalities in the region: Kuteesa et al. (2014) show that older adults' experiences of HIV-related stigma vary by their physical health, financial independence and availability of social support; Richards et al. (2013) indicate that older age increases the vulnerability of older adults with and to HIV. Participants in their study reported that widely-held expectations of older adults' non-sexual behaviour meant that they were excluded from both sexual health information messages and services delivered by younger practitioners with whom it would be inappropriate to discuss sex.

Understandings of the nature of stigma in these African studies are varying and partial. As research from outside Africa, they do not examine whether there are differences between the HIV-related stigma experienced by older and younger people, or compare the stigma experiences of older adults with and without HIV. Moreover, we know almost nothing about

the source of the stigmas they allude to: what understandings about older age and HIV underpin their being considered 'discrediting attributes' or how these two sets of understandings come together to produce layered stigma. What did older participants in the Togolese study think was implied about them if they were identified as having HIV? What is it about financial independence that alleviated or exacerbated HIV- and age-related stigma for older adults in Uganda? Why is physical health important for perceptions of stigma? Challenging stigma as part of an effective response to the shifting HIV epidemic will require answers to these questions.

Studies of HIV+ older Africans' perceptions of stigma follow an analytical tradition in HIV research of focusing on those whose attributes are stigmatised, the perpetuators of HIV-related stigma and the individual-level interactions between them. Individual-level interventions grounded in such research have had limited success (Stangl et al., 2013). Subsequently, there have been calls to widen the analytical lens to situate HIV-related stigma within the wider macro-level social, political and economic context of individuals' experiences and interactions in order to better understand the source of stigma.

Recognising that stigmas are part of complex systems of beliefs about illness, other studies frequently link stigma to existing macro-social inequalities, such as poverty and gender inequity (Castro & Farmer, 2005). For example, the phenomenon of 'resource-based stigmatisation' refers to the influence of poverty in shaping attitudes to individuals with HIV leading to the social devaluation of those perceived to be economically unproductive due to illness and economic-related discrimination in which investment of resources in people with HIV/AIDS is considered a 'waste' (e.g. Bond, 2006). Such approaches draw attention to the emphasis on social relationships Goffman's definition of stigma, and argue that addressing

stigma will involve addressing not only the attitudes and activities of individuals but also the mechanisms of dominance and exclusion.

But stigma clearly has individual level dimensions: it is at the individual level that stigma is reproduced, experienced and resisted. A third body in the diverse literature on stigma and HIV therefore calls for analyses that consider both individual and macro-level experiences and causes of stigma. For Link & Phelan (2001) stigma is the co-occurrence of labelling, stereotyping, categorical in group/out group separation, status loss and discrimination. Crawford's (1994) work on the process of labelling and separation with regard to AIDS in middle-class America illustrates how these processes span individual and macro levels. He argues that individuals identify and label out-groups based on fear of the 'unhealthy' and distance themselves from the threat posed by membership of this out-group through separation. While individuals do the 'othering' as part of creating and recreating the self, what is considered 'other' –what is feared – has biomedical and metaphorical meanings that extend beyond the individual to reflect wider, context-specific, power differentials.

I take as my starting point the understanding that stigma is a fluid and contested social process, rather than a static attitude; that it is imbedded in shared meanings and ideas that are sustained through interactions and relationships and that it is enacted and experienced by individuals. In this paper I present meanings of older age and HIV that underpinned the othering and social disqualification of older adults with HIV expected by participants in a study in Malawi. These meanings are individually reproduced, but based on shared understandings that transcend any individuals' narratives and experiences. As abstractions created to help understand the world, these meanings are context-dependent. Those I present are grounded in the specific, historically-situated macro-structure of rural livelihoods in this

setting. They are underpinned by social processes that are ultimately concerned with relations of power and are rooted in social inequalities.

I discuss older adults' efforts to resist HIV-related stigma elsewhere (Freeman, 2012). Here, in exploring the representations through which stigma of older people with HIV are perpetuated, I contribute new evidence that could support interventions to address the causes and shape of stigma.

METHODOLOGY

I present qualitative data from 12 months of fieldwork (2008-2010) in and around Balaka District, southern Malawi. Since so little is known about ageing with HIV anywhere in Africa, no specific hypotheses were identified at the outset of the research. Instead, I used constructivist grounded theory (Charmaz, 2006) to generate and analyse data that privileged what older adults themselves presented as salient elements of their experiences and values. This research design, encompassing interconnected ontological, epistemological and methodological assumptions, emphasises the simultaneous collection and close analysis of data generated to capture social connectivity and fluidity. In light of its constructivist approach, the ultimate goal of the research was the analytical interpretation of the ways older adults in Balaka made sense of their realties with regards to ageing and HIV, at the same time recognising that any interpretation is problematic, relativistic, situational and partial (Charmaz 2008:470).

The primary method of generating data was a series of in-depth interviews with adults aged between approximately 50 and 90 years old. The content of interviews varied between participants and over time. Emerging analytical ideas were discussed with participants to ensure their credibility. As more data were constructed and analysed, interview questions became more specific as ideas were explicated, the relationships between them were

examined, and the analytical categories and themes most important for shaping participants' understandings and experiences became clearer to me.

I used theoretical sampling to identify participants, maximising variation in the analytical categories being developed so that experiences could be juxtaposed and examined (Corbin & Strauss, 2008). This was possible because I knew something of the characteristics (e.g. age, gender, HIV) of potential participants before approaching them: they were randomly recruited from stratified samples of those who had participated in the Malawi Longitudinal Study of Families and Health (MLSFH) (see Anglewicz et al., 2009), which this study forms part of (n=23), and purposively recruited from the families of existing participants (e.g. parents, spouses) (n=9), HIV support groups and the local area (e.g. traditional healers) (n=11).

This paper draws on data from multiple interviews (N=135) with men (N=20) and women (N=23) living in approximately 25 small, rural villages. Just under half (n=18) had HIV. Interviews presented here were conducted in Chiyao or Chichewa with the help of local research assistants between March 2009 and May 2010. Spending time with participants was central to the methodology used: most participated in audio-recorded interviews three or four times over the course of several weeks, each interview typically lasting one or two hours but sometimes much longer.

Interviews covered a wide range of topics (HIV and growing old, but also relationships, politics, day-to-day life and more) and sought to identify both ideal statements and descriptions of practice (what actually happens). This paper is concerned with the shared understandings that led participants to recognise HIV in older age as a discrediting attribute. I therefore privilege the normative lenses through which participants perceived the world around them (the ideal statements) in my discussion, rather than assumptions about or

described experiences of the enactment of stigma. The understandings presented do not necessarily represent normative harmony in the fieldsite, neither do they imply homogeneity in participants' experiences.

Interviews and my analysis of them were additionally informed by analysis of data from: observations made during visits to participants' homes throughout fieldwork; group interviews with members of three HIV support groups (N=3); and initial in-depth interviews with older adults (N=42), conducted between June and August 2008 in all three regions of Malawi, to explore the salience of HIV for older adults and identify any issues that were important for older adults but which I had not considered in designing the research.

Ethics

All participants consented to take part in the study following lengthy explanation of the research that took account of any age-related decline in vision or hearing. The study was described as being about growing older and HIV generally, rather than about HIV infection in older age or among participants. Participants recruited via HIV support groups were widely-known to have HIV from 'sensitisation' work they did in their communities. Although I was aware of the results of MLSFH-provided HIV testing for participants recruited this way, this information was not shared with research assistants who did not question participants about their HIV serostatus, but left them to disclose this during interviews if they wanted to. All participants known to me to have HIV introduced the topic of their infection during our conversations. In addition, all participants who expressed desire to be tested for HIV were provided transportation to HIV testing centres.

Reflecting social norms around visiting and good ethical practice among researchers in Malawi, participants received small gifts when visited for a research conversation. These

were presented to participants on greeting, irrespective of whether an interview was subsequently conducted.

Permission to conduct research was granted locally by village heads, HIV support group leaders and district branches of the National Association of People Living with HIV/AIDS in Malawi, nationally by the National Health Sciences Research Committee, and internationally by the London School of Economics and Political Science Research Ethics Committee.

ANALYSIS

The research site, rural livelihoods and centrality of 'adulthood'

Balaka is one of the poorest districts of Malawi, one of the poorest countries in the world (World Bank, 2016). It is overwhelmingly rural, and in this regard representative of Malawi's population, 85% of whom live in rural areas (NSO, 2008). Food insecurity is common and increasing (Verheijen, 2013). All participants and their families experienced food shortages, at least during the annual 'hunger season'. Livelihoods centre on subsistence (maize-based) agriculture for which the hoe is the main tool. Few participants had livestock (chickens and goats). Household and individual survival is therefore ultimately bound-up with ability to support oneself and one's family through primarily body-centred agricultural production, and to invest in relations of social interdependence that underpin access to farming land and the familial and community support relied upon when an individual's capacity for self-sufficiency is temporarily or permanently limited (Englund 1999; Freeman, 2016).

Almost everyone contributed to their household's survival in the fieldsite. Children carried water, washed plates and when big enough, pounded maize. Even in advanced old age, individuals farmed as their strength permitted. Work constituted daily routines and included

material and social production. Farm-, paid-, house- (including reproduction, caregiving and giving advice) and "bed-" (marital sex) work were all understood to contribute to the very making of persons and households:

> *Aaah! I will stop working when I am dead. No matter how old I am, I will continue working... For your daily life, you have to work. You have to work for the life you are living.*
>
> [Lyness, male, 68, HIV-]

> *Everybody is supposed to do working at this home. Yes everybody…For a place [home] to be known as a place one has to work.*
>
> [Youngson, male, 70, HIV-]

Ability to work corresponded with both having and attaining bodily, moral and social power. Participants spoke frequently of the respect awarded to those who were self-sufficient and supported others. Moreover, while successful production (e.g. creation of food, money, children) imbued workers' positive traits with a tangible reality, in participants' narratives the act of working, to an extent regardless of output, demonstrates one's status as a living person:

> *R To work [is] to achieve something. You farm in order to harvest the maize. You wash your clothes to put on clean clothes. You go and fetch water to be used at home… Everything has its own importance.*
>
> *I So you think, what are the results of just staying [not working]?*
>
> *R It's like you are dead… Dead when you are alive.*
>
> [Rhoda, female, 56, HIV-]

> *My body is weak and I don't have strength. I am just doing the work because I am a [person], I cannot do otherwise.*
>
> [Patuma, female, 58, HIV-]

In participants' descriptions of daily life, those who did not work were disengaged from the social world, physically and socially; in my observations in the field site, such people were rarely present outside the private space of the compound. In this way, work produced not only entitlement to physical life (secured survival) but also social life. 'Adulthood' was the term most frequently used to describe this state of being and belonging to the social world, embodied in the act of work. Those who did not work failed to produce their adulthood. Typically only the very old or chronically very sick occupied this position. They were described as "children" by participants, an analytical notion and label distinct from chronological or biological age used to emphasise their powerlessness.

Dominant understandings of older age

Although there were considerable differences in participants' ageing experiences, they all described both experiences and expectations of ageing that were invariably embodied. The body was central to understandings of what old age 'meant'. In participants' narratives, old age is described in overwhelmingly negative terms as a linear decline in bodily power.

For participants, a body's power was primarily determined by the quantity, flow and temperature of its fluids, described as containing a life force – a quality of 'being alive'. In conversations about ageing, all bodily fluids and the power they both contained and equated to were referred to as "blood", "power" and "strength":

P The importance [of blood] is that it makes the body strong, but when you don't have adequate blood you are weak…When they say a person is strong, it's the power of the blood.

I When talking about blood, are you talking about the actual blood, or semen or just power?

P Those things all contribute to make strength…Strength and blood go together… Blood is strength. Not that strength is in blood, not, but blood is strength. Because they both go together.

[Thomas, male, 60, HIV-]

In very old age, an individual's blood was understood to thin, cool, cease flowing and eventually dry out. This left the old body with little strength:

When a person is born he has all the strength… Each passing day the strength is removed little by little… And when he is growing very old it goes down … It all ends when God has taken you back to him.

[Robertson, male, 80s, HIV-]

Gradual age-related decline in bodily power was understood to be inevitable and irreversible. Participants in good health occasionally commented that they were subsequently at ease with ageing. However, all participants discussed fearing a time their power would decline more rapidly. They relied on potent imagery to describe this period of life in which both power and the person would be "finished":

Nowadays I am frequently attacked by illnesses…I can't say [why] because that is God's plan: what God has sent to you is yours. It's like when a tree starts rotting, the same is to human beings…The coldness is there…it shows he is not strong… The younger one has fresh blood while the older one has finished blood.

[Charles, male, around 70, HIV-]

Decline in power was measured by and experienced with reference to physical strength to 'do'. Old bodies could not farm, do housework or reproduce. Participants who recognised

themselves as older adults did so based on their experiences of declining strength and productivity:

> *The children would come and say let us do it for you, you are old now. That was when I knew that I am becoming old - when I couldn't do all the things I used to do.*
>
> [Winford, early 80s, male, HIV-]

In the dominant discourse described in the interviews therefore, the body is a social, as well as physiological phenomenon. It was the old body's inability to work and produce - interpreted within the social and structural context of participants' lives - that underpinned it being understood as "finished". Through production, the body contained the possibility for development and positive change, whether through having a child, amassing wealth, remarrying or constructing a house. Without strength, life lacked potential and the body became "useless".

However, despite some experiencing considerable limitations in their functional ability, no participants identified with the powerless "child-like". Instead, those with less bodily power focused on their social power as morally-productive members of their households and communities – custodians of wisdom and good morals, and the givers of advice: that is, workers, and subsequently 'adults', of a different sort.

This understanding of old age is represented by 'the elder' in participants' narratives. In the narratives, the elder avoids gossip and is wise, restrained in pleasure-seeking and anger, forgiving and generous. Here Fiskani contrasts his expectations of failing bodily work with non-physical, social work. By focusing on his wisdom and advice-giving, he presents even his future self as occupying contributory roles that will define him as an 'adult':

I *The last time we met you told me that the best time in a man's life is when he is young because he is independent and can do everything for himself. What then is good about being your age?*

P *What I see at my age is that I now can abstain myself. I avoid a lot of things, I don't quarrel with people, so your life is better… Being very old is good but not to the point of being helped to do things or being carried…My family benefit from me in many ways… we do assist each other on the work which we undertake in this compound, I act as the foreman…They also can learn things on how to live and also I am the one who supports the family…[In 20 years' time] from me there is nothing they will benefit [physically], but they will benefit in that I will be able to give them advice [and] I am a weaver, I can still give instructions on how to weave a good mat.*

[Fiskani, male, 61, HIV+]

Participants dismissed those without the ability for moral or social production as being "childish". For example, John distances himself from the child-like young and old because of his wisdom, here with regard to the risks of sex:

P *The youth of today, they are Bantam* [a newly imported maize variety that could be harvested more quickly than 'local' maize]. *They grow fast, but with no reasoning capacity to say 'at this age what am I supposed to be doing? At this age how can I be aware of the girls? How dangerous they are?' But we the locals* [maize: older adults]*, we are able to reason…*

I *What qualifies one to be an old person?*

P If first that person accepts the situation that he is aged, because there some aged people who behave like children.

[John, male, 63, HIV-]

In participants' narratives while older adults' moral power secured their membership of the social world (the in-group) when bodily power waned, old age itself was neither sufficient nor prerequisite for attaining this power. Advice and leadership roles (e.g. village heads, marriage advisors and leaders of initiations) were often occupied by younger adults. Moreover, older adults could be foolish. While participants drew parallels between their own productive endeavours and the wise elder trope, they frequently ascribed an old age devoid of physical, moral and social power for others:

We had a certain old man, he just died recently. He couldn't walk out of the house by himself, he couldn't do things on his own. His grandchildren would pick him to go outside to have the sun, he could be crying… He was just like a child, he could even fear a goat, when it is [only] a goat!

[Alick, male, early 50s, HIV+]

Participants drew a clear distinction between productive older adults who retained power and the unproductive very old who had no power. The possibility of a childlike old age in the absence of bodily, moral and social power was a reoccurring narrative and a feared status. This possibility underpinned understandings of the implications of HIV in old age.

Dominant understandings of HIV in older age

Participants' understandings about HIV in older age were remarkably similar. Understandings offered by participants with HIV did not differ from those offered by

participants without HIV. Instead those with HIV challenged HIV-related stigma by differentiating themselves and their experiences from shared understandings (see Freeman 2012).

Conversations about HIV centred on its transmission and prognosis. Three characteristics were central to understandings of HIV in old age: that HIV is most frequently transmitted via socially unsanctioned sex; that HIV weakens the body, eventually causing death; and that subsequently, HIV-infection requires intensive care. While these understandings were relevant for infection at any age, in participants' narratives they have explicitly age-related nuances, based on understandings of the importance of work for the production of adulthood and the decline in power that accompanied growing old. Through each of the three characteristics, HIV was understood to accelerate and reflect an older individual's trajectory to the child-like status by challenging and questioning their physical, moral and social power to produce adulthood.

The sexual transmission of HIV

Participants directed conversations about HIV towards its sexual transmission, specifically via *chiwerewere* (non-marital sex). In their stories individuals were infected relatively recently (a lag between infection and diagnosis was rarely discussed) and most commonly through *zibwenzi* (non-marital sexual partners, typically understood as boy/girlfriends), sometimes concurrent with a marital partner. Therefore *chiwerewere* also undermined the safety of marital sex by exposing an individual to the risk of HIV from their spouse or co-wife's present and past *zibwenzi*.

The significance of sex for HIV transmission had implications for participants' understandings of the inevitability of infection. In the first narrative, more common among participants with HIV, nobody "chose" to become infected. Since sex was generally

understood positively as both God-given and necessary, HIV risk was considered to be systemic. Further, even if individuals were able to abstain from sex completely, they could not avoid infection if it was God's plan for them:

> *[HIV] is from God … because if you follow everything to prevent yourself from getting it, you can maybe have a complex situation, where you will need to help deliver a baby in an emergency, and there are no means of protection, you can get it, even though you have been very careful.*
>
> [Doris, female, 70s, HIV+]

However in a second, much more dominant narrative, natural and near-universal desire for sex was superseded by the bombardment of HIV messages. Since individuals had agency with regard to acting on their sexual desires, in this narrative, those with HIV had chosen to become infected. In the context of HIV, *chiwerewere* indicated a "lack of self-control":

> *I think that if that person took heed of advice given about AIDS they would not have been in that situation because each time we go to the hospital… we are sensitised about AIDS. Even on the radio - issues about AIDS are there.*
>
> [Mercy, female, 50s, HIV-]

> *The first thing that [my wife] told me [when I told her I had HIV] was 'that is what you wanted, because I knew you were doing* chiwerewere. *You were leaving me here, and going out to look for other women, because of this you have what you wanted'.*
>
> [Daniel, male, early 50s, HIV+]

Significantly for understandings of HIV in later life, an individual's ability to control their sexual urges was considered to be age-related. According to participants, younger adults frequently engaged in *chiwerewere* despite being aware of the risk of HIV infection. In part, this reflected the physiological differences between old and young bodies discussed. Sexual desire was concomitant to the heat of one's blood. Since bodily fluids cooled with age, participants reported that it was more difficult for younger adults to resist the natural call to *chiwerewere*:

> *When it's [HIV] found with a young person, they say 'let's put that aside'. They say with young people 'how could they keep themselves? They need to eat each other [have sex], that's nature'.*
>
> [Esnart, female, mid-60s, HIV+]

> *[When younger adults are infected] people say it's obvious. Because at that age you have to do sex with a number of girls, and we used to do that too during our time.*
>
> [Youngson, male, 70, HIV-]

Nevertheless, resisting *chiwerewere* in older age still required effort. Rather than reflect the total cooling of blood and therefore sexual desires, sexual restraint in older age was offered as evidence of good judgment and moral power. The presentation of sex in conversations about HIV differed therefore from those given within the context of conversations about ageing and sex. In conversations about ageing, participants stressed their sexual ability and frequency of intercourse in order to underline their continued bodily power and productive capacity (Freeman, 2014). In the context of HIV, participants instead drew on the elder trope to stress their moral power to overcome the heat of their blood to refrain from sex in order to protect both their and their spouse's health and ability to work.

Sexual behaviour that was understandable for younger adults was therefore not socially-sanctioned for older adults:

I Do people react the same when a young person has [HIV], as compared to an old person?

R It is not the same. People speak a lot of bad things.

I Who is talked about more?

R They talk bad about us, more than the young people. Because we are old. They say 'an old person is found with this disease? Eeee! They are big prostitutes'

[…]

I You said if the [support] group was composed of young people, you would be ashamed. Why?

R Because I would have been thinking that out of all the group, I am the only old person. The youth would have been saying 'but that woman [tuts and shakes her head], arrh! It's better us, the young people'

I So you mean, being promiscuous? It's fitting for young people?

R Yes

I And not you old people?

R Yes, it's not our size. It's not our size.

[Nyuma, female, 68, HIV+]

Older men and women with HIV were subsequently understood to lack the moral power required to refrain from *chiwerewere*. As a result, they forfeited the social power and respect they ought to have attained. Without moral or social power, older adults with HIV could not carry out the moral and social work of advice-giving. That is, they lacked the capacity to produce their adulthood this way. Winford here explores how this inability to secure social power prevents participation in the social world through kin- and community-based relationships. His description accords with those given by participants with and without HIV:

> *The problems will come because the youth will say 'this person is troublesome'. They will say 'we were thinking they were respectable old people, but they are not, they have AIDS'. So can you advise the young people? It can't happen… It is hard because, you also have the disease, and you want to advise them against AIDS, [but] they will say 'why is he advising us when he himself has it?' They will say 'if he knows it was a bad thing, why does he have it himself?' So you just keep quiet.*
>
> [Winford, male, early 80s, HIV-]

Participants who had been diagnosed with HIV in later life discussed their initial response in terms of shifted perceptions of their behaviours. In their narratives, HIV in old age unlike HIV in younger age is a social identity, involving not just an individual's body, but their character. Their accounts suggest internalisation of these perceptions. When Esnart was diagnosed with HIV when aged in her 60s, the change in peoples' perceptions of her was the most salient element of her experience:

> *My worry came because when a person has been found with the disease, people take them as foolish. So I said, 'should people know, I am sick like this?' I will be a foolish person, I will be like a lost person. I will be a nobody. When I used to be*

someone who was respected… I was crying for this story, the whole of my crying centred there.

[Esnart, female, mid-60s, HIV+]

Esnart's narrative, as those of other participants, closely accords with Link and Phelan's (2001) definition of stigma. She expects others to label her behaviour as foolish and subsequently categorise her within the out-group, resulting in her status loss and exclusion from society ("I will be like a lost person. I will be a nobody").

HIV at old age means death "at any time"

Conversations about HIV oscillated between the routes to infection, and the prognosis of those infected. Understandings of HIV pathogenesis reflected participants' broader understandings of blood (power). When the body contained a lot of blood, it was able to defend itself against the virus for longer; when the body contained less blood, it had less power to withstand the virus. Since ageing for participants involved a trajectory of declining blood, HIV was understood to be more potent in older, already weak bodies than in younger bodies. It presented a further challenge to retaining bodily power in older age, "complicating the situation" of ageing and signalling that the body's blood would soon be "finished":

R The older one can die easier. The younger would remain but later he will also die because the disease is AIDS.

I Umm, why did you say the older one would die quicker?

R Because he has no blood… it is finished .

[Charles, male, around 70, HIV-]

Although participants understood the virus would inevitably empty both old and young bodies of blood, they reported that it was possible to fortify the blood and its defence to delay death. Consuming "good food" - meat, eggs, cooking oil - increased the body's power. Significantly, securing this expensive protein- and calorie-rich food is labour-intensive. Old bodies, already experiencing a decline in physical power, were understood to be less able to perform such labour or motivate others to provide it by investing in social relationships. The effect of HIV on old bodies was therefore cumulative:

> *So the aged will die fast [from HIV] because their bodies are already weak, whereas the girls are strong, and they are able to get help and they eat nice food… So when you are aged, where are you going to get them? You die the same month… Whereas the girl will be able to buy [the food]. So she will be gaining the strength, when you [an old person] are only eating the vegetables, so can it work?*
>
> [Rhoda, female, 56, HIV-]

The social construction of older adults with HIV as lacking power for physical production underpinned HIV-infected participants' stories of being overlooked for paid work or not receiving coupons for Government-subsidised fertiliser distributed by village heads on the grounds that the limited and valuable coupons would be wasted on them. Although this discrimination was not unique to older adults with HIV, participants argued it was more common in old age because of these understandings. In the following excerpt, Cidreck makes the link between being perceived as unable to work and invest in one's future and social exclusion:

> *The village heads do not understand us [older adults]. Like with piecework, we are not considered. They think we can't work: we just want to get free money… when someone has HIV or AIDS, they think they are people who get sick very often, and*

that they are weak. They are not useful… That is why we are sidelined, and left behind.

[Cidreck, male, 50s, HIV+]

Exclusion of older adults with HIV from full participation in the social world went beyond their ability to carry out physical work to secure resources that might strengthen their blood. In participants' narratives, the very physical viability of older adults with HIV is questionable. Since older adults with HIV are "weak and unhealthy" [Estina, female, 55, HIV-], they are expected to be vulnerable to very small threats to their health. Even "bumping a tree stump" could result in death [Mercy, female, 50s, HIV-]. When Robertson said "if I would be found with [HIV]…I would just say I am a dead person" he was not only referring to the eventual death understood to be inevitable for anyone with HIV. He referred to a reoccurring image in the interview narratives of older adults with HIV as *maliro* [corpses].

The availability of ART had done little to alter these understandings. Narratives about the use of ART, particularly in old age, were confused and contradictory as both infected and non-infected participants weighed experience or stories about the success of treatment against the funerals they had attended over the years. On one hand, ART, referred to as *chitetezo* (protection, immunity), was understood variously to strengthen the blood, or provide a protective layer "which the disease feeds on, instead of feeding on person's body" [Lyness, male, 68, HIV-]. On the other hand however, longstanding public health messages that "HIV has no cure" were difficult to forget. Non-infected participants acknowledged that infected adults now grew fat and so appeared healthier, but were sceptical about whether this signalled improved strength. Instead, ART was presented as providing a bodily mask that hid the on-going weakness of blood beneath. Without physical viability, older adults with HIV had no

social viability. In the following excerpt, the social segregation of those occupying this position is explored in terms of their exclusion from humour, an important mechanism for building social ties in the field site:

> *A person who is suffering from malaria, and the other one who is suffering from [HIV]… They are different because a person who is suffering from [HIV], although a person will suffer and recover, the body is still weak… So that is what people say at the borehole, or anywhere they will meet. They used to say when they see a person who suffered [of another illness], when that person arrived they start to talk to that person that, 'you were serious [ill] but now your body is back to normal', like praising them. But to others who suffer from [HIV] we just greet them. We don't joke with them. We know that although a person has recovered, the body is still weak, so we don't talk more to them, so people just gossip on them [when they have left].*
>
> [Mercy, female, 50s, HIV-]

Even among HIV-infected participants, there was some doubt about the efficacy of ART in old age. Later rates of ART initiation and subsequent higher mortality among older adults were locally interpreted as evidence that that the strong medicine would overwhelm the weaker blood of older adults, hastening death:

> *With the medicine, we see [older] people taking them, then they die after sometime. So we say maybe when we take the medicine, maybe it weakens us so that we die earlier? This is not from counselling, it is what I think on my own. The young people do die also, but mainly it's us old people who die faster. Maybe we have insufficient blood in our body.*

[Stella, female, 70s, HIV+]

In participants' narratives therefore, older adults with HIV are more likely than younger adults with HIV to lack the bodily power through which they could make economic (e.g. by farming) and social (e.g. by sharing jokes) investments in either their physical health (through fortifying their blood) or the social ties that secured their full membership of the social world.

HIV requires intensive caregiving

Before inevitable and (more) rapid death, older adults with HIV were understood to require intensive care. Narratives typically centred on fear that in the absence of spouses and same-sex siblings, participants' children would be relied upon to provide this care. Receiving care had implications for the care recipient's place in the social world of adults, resulting in loss of social power.

Firstly, HIV-related care at old age, unlike age-related care without HIV, was understood to always involve intimate care centred on cleaning and preparations for inevitable and ubiquitous diarrhoea. These care tasks necessitated the caregiver "seeing the private parts" of the recipient. When the recipient was an older adult and the caregiver was their child, the situational meanings of intimate physical dependency and bodily exposure were considered to be humiliating. It represented for participants the reversal of parent-child behaviour and the recipient's status as an adult.

> *It is not good be cared for by your child when you have this disease. Yes, it is not good. The children should be sick and you should be taking care of them. Yes, because it is a very bad disease. Somebody down there [in the village] she was wearing nappies like a child… So should your child be doing that for you? Is that*

good? No, it is not good. It's better to die of another disease. Yes, but not AIDS. You lose respect because it brings very bad illnesses… The other bad thing is that the child is even able to see your private-parts which is not good… It is supposed to be you cleaning the private-parts of the child… but not the child doing that…if you are still alive you still feel ashamed: my own child cleaning my private parts!

[Rhoda, female, 56, HIV-]

Secondly, care for older adults with HIV was understood to both deplete a household's resources and limit future production. Care involved securing blood-strengthening high-cost and -calorie food, creating a financial burden on families that was frequently cited and feared by participants with and without HIV. In this resource-poor setting, when a caregiver was a son or daughter with his or her own children to feed, the shame involved in creating this burden was even greater. Further, intensive care prevented caregivers from farming to produce food, deepening the burden on the household:

"If I can get [HIV], it will mean that I have put my children in troubles, because they have got their children who are relying on them. Their children are struggling; they don't have enough food.

[Patuma, female, 58, HIV-]

Burdening the family with caregiving tasks was similarly incongruent with the meanings of adulthood. Individuals who required care were provided for by their families but contributed nothing to their families' survival. The meanings of such behaviour (selfishness, lack of love or "just staying") could not be considered morally or physically productive. In asking for "everything" from their families until their families are left with "nothing", in participants'

narratives older adults with HIV cannot earn the social power they would otherwise have produced in older age even if sick or decrepit:

> *To those who don't suffer from disease of AIDS, when they become sick, we bathe them. If it is me, children bath me, making me clean… But AIDS, people go disrespectfully. Disrespectfully. Everything, everything! [Points to imaginary food] …Nothing remaining at home. Nothing!*
>
> [Ruth, female, late 70s, HIV-]

CONCLUSION

Older adults with HIV have specific needs and realities. For example, there is evidence to suggest that in Africa, as in high-income countries, older adults are typically diagnosed with HIV later and with lower CD4+ cell counts than younger adults, making treatment less effective (Negin et al., 2011). Older adults who diagnose late are substantially more likely to die within a year of diagnosis than older adults who are not diagnosed late or younger adults who are diagnosed late (Smith et al., 2010). The stigma of HIV in older age is expected to influence late diagnosis. Research and subsequent interventions to target older populations and address HIV-related stigma are needed.

Stigma-focused interventions should be grounded in knowledge of the source of stigma. However stigma itself is rarely the unit of analysis in studies focusing on older populations. Previous studies have tended to describe older adults' expectations of being stigmatised or discriminated. This study is one of the first to conduct a detailed investigation of the relationship between meanings of older age and HIV that underpin understandings of HIV in older age as a discrediting attribute.

In Balaka, Malawi, these understandings centred on age- and HIV-related loss of the bodily, moral and social power required to produce one's membership of the social world through the performance of one's own survival and that one's kin. Older men and women frequently referred to those unable to work to secure this status of being and belonging as being "like children" (terminology also observed in Botswana (Guillette, 1992) and Kenya (Cattell, 2002)). That work is important for building social relationships and attaining social power has been observed in a variety of African settings and historical periods (Englund, 1999; Alverson, 1978; Comaroff and Comaroff, 2001; Hammond and Jablow, 1976; Livingston, 2002). Many of these studies have observed that older adults continue to work into very old age to prevent negative social labelling. For example, in a setting also dominated by agricultural production and familial support networks, Maria Cattell's ethnography of the Abaluyia in Kenya identifies the importance of being "active" and "useful". She notes how even the frailest older adults work in their fields and homes, observing that "it is their way of claiming full personhood and worthwhileness. To be considered or to feel useless calls into question one's value as *omundu* – a person, a human being" (Cattell, 2002: 170).

Ethnographic writings on the life course globally have frequently made a distinction between older adults in their productive prime and very old people, who are less productive and subsequently play marginal roles in society. The association between membership of the social world and productivity is reflected in the names that have been documented for this group: the "old-dead" among the !Kung/Ju/'hoansi of Botswana (Lee, 1992:43; Rosenberg, 2009:32) and the "completely far gone" among the Akan of Ghana (Apt, 1995:17).

In this paper, I argue that understandings of older adults' productive capacity interacted with understandings of HIV to produce age-specific meanings of HIV. HIV was expected to limit older adults' productivity, both reflecting and resulting in *magnified* loss of physical, moral

and social power. Without power, older adults with HIV were aligned with the out-group previously only occupied by the "child-like" very old who are unable to fully participate in the social world. In this way, understandings of power arising within social relationships underpinned conceptualisations of ageing and HIV that layered age-related and HIV-related stigma.

Differences in material and political power reinforce the stigmatisation of older people with HIV. At the material level, in Balaka the fragility of livelihoods was a potent driver of negative understandings of HIV in ageing. The importance of self and familial provision was grounded in the context of widespread poverty and common experience of hunger. The influence of limited material contribution and financial receipt on the social status of those with HIV has been identified in other African settings, including among middle-aged and older participants (Holmes & Winskell, 2013). In this study, negative perceptions of HIV in older age were linked to perceived failure to contribute to familial survival through physical (material) as well as moral and social production.

At the political level, the findings additionally provide insight into the way age- and HIV-related stigma are produced and reproduced through the operation of power in social relations that mirror existing fault lines. For example, negative perceptions of HIV in older age were compounded by understandings of the moral power older adults ought to possess in light of their decreasing bodily power for production. While HIV at all ages was understood to imply recent sexual activity, cooler older bodies should have been able to resist sexual temptation to protect their families. Older adults with HIV were therefore understood to have failed to be morally productive in a way their younger counterparts had not.

Limitations and areas for future research

The research participants were all older adults. I therefore missed perspectives from other actors that would have contextualised older adult's understandings and allowed comparisons to be drawn. For example, the systematic inclusion of younger adults with HIV may have further highlighted the effects of older age on experiences and expectations of HIV-related stigma identified.

Secondly, academic and grey literature has consistently highlighted the central role of gender for increasing vulnerability in old age in Africa. However, (and in accordance with previous research on gendered power relations among younger women in Malawi (Schatz, 2005)), gendered differences in the sources of HIV- and age-related stigma were not salient in the narratives of participants in this study. Nevertheless, it is possible that in other settings, gender (or indeed other attributes) promotes a third layer of meanings that may interact with old age and HIV and deserves investigation.

Finally, while the utility of considering the meanings of HIV and older age for producing evidence to support stigma reduction interventions is a transferable concept, the study did not aim to identify meanings that would be applicable to understanding HIV- and age-related stigma in other settings. Both the heavily context-dependent nature of the meanings discussed in this paper, and the ageing of the HIV epidemic itself, remind us that responding effectively to the epidemic will not entail a single, universal approach.

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