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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 (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.

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

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

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

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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 (Emlet, 2006).

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 varied 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 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 and 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 and 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 individual's 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.

1. 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