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## Understanding HIV-related stigma in older age in rural Malawi

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# 1                    **Understanding HIV-related stigma in older age in rural Malawi**

## 2   **Abstract**

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

11   Dominant understandings of HIV in Balaka pertained to the sexual transmission of the virus  
12   and poor prognosis of those infected. They intersected with understandings of ageing.

13   Narratives about older age and HIV in older age both centred on the importance of having  
14   bodily, moral and social power to perform broadly-defined "work". Those who could not  
15   work were physically and socially excluded from the social world. This status, labelled as  
16   "child-like", was feared by all participants.

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

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

26

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35 people aged over 60 in Uganda. *African Journal of AIDS Research*, 12, 71-78.

36

## 37 **Keywords**

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

39

## 40 **Research highlights**

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

46

47

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.

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

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

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

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

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

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

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

120 But stigma clearly has individual level dimensions: it is at the individual level that stigma is  
121 reproduced, experienced and resisted. A third body in the diverse literature on stigma and  
122 HIV therefore calls for analyses that consider both individual and macro-level experiences  
123 and causes of stigma. For Link & Phelan (2001) stigma is the co-occurrence of labelling,  
124 stereotyping, categorical in group/out group separation, status loss and discrimination.

125 Crawford's (1994) work on the process of labelling and separation with regard to AIDS in  
126 middle-class America illustrates how these processes span individual and macro levels. He  
127 argues that individuals identify and label out-groups based on fear of the 'unhealthy' and  
128 distance themselves from the threat posed by membership of this out-group through  
129 separation. While individuals do the 'othering' as part of creating and recreating the self,  
130 what is considered 'other' –what is feared – has biomedical and metaphorical meanings that  
131 extend beyond the individual to reflect wider, context-specific, power differentials.

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

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

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

## 147 **METHODOLOGY**

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

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



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

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

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

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

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

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

#### 198 *Ethics*

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

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

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

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

## 218 **ANALYSIS**

### 219 **The research site, rural livelihoods and centrality of ‘adulthood’**

220 Balaka is one of the poorest districts of Malawi, one of the poorest countries in the world  
221 (World Bank, 2016). It is overwhelmingly rural, and in this regard representative of  
222 Malawi’s population, 85% of whom live in rural areas (NSO, 2008). Food insecurity is  
223 common and increasing (Verheijen, 2013). All participants and their families experienced  
224 food shortages, at least during the annual ‘hunger season’. Livelihoods centre on subsistence  
225 (maize-based) agriculture for which the hoe is the main tool. Few participants had livestock  
226 (chickens and goats). Household and individual survival is therefore ultimately bound-up  
227 with ability to support oneself and one’s family through primarily body-centred agricultural  
228 production, and to invest in relations of social interdependence that underpin access to  
229 farming land and the familial and community support relied upon when an individual’s  
230 capacity for self-sufficiency is temporarily or permanently limited (Englund 1999; Freeman,  
231 2016).

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

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

238 *Aaah! I will stop working when I am dead. No matter how old I am, I will*  
239 *continue working... For your daily life, you have to work. You have to work for*  
240 *the life you are living.*

241 [Lyness, male, 68, HIV-]

242 *Everybody is supposed to do working at this home. Yes everybody...For a place*  
243 *[home] to be known as a place one has to work.*

244 [Youngson, male, 70, HIV-]

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

250 *R To work [is] to achieve something. You farm in order to harvest the maize.*

251 *You wash your clothes to put on clean clothes. You go and fetch water to be*  
252 *used at home... Everything has its own importance.*

253 *I So you think, what are the results of just staying [not working]?*

254 *R It's like you are dead... Dead when you are alive.*

255 [Rhoda, female, 56, HIV-]

256 *My body is weak and I don't have strength. I am just doing the work because*  
257 *I am a [person], I cannot do otherwise.*

258 [Patuma, female, 58, HIV-]

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

#### 268 **Dominant understandings of older age**

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

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

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

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

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

285 [Thomas, male, 60, HIV-]

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

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

291 [Robertson, male, 80s, HIV-]

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

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

301 [Charles, male, around 70, HIV-]

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

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

306 *The children would come and say let us do it for you, you are old now. That was*  
307 *when I knew that I am becoming old - when I couldn't do all the things I used to*  
308 *do.*

309 [Winford, early 80s, male, HIV-]

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

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

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

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

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

339 [Fiskani, male, 61, HIV+]

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

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

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



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

351 [John, male, 63, HIV-]

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

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

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

364

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

### 369 **Dominant understandings of HIV in older age**

370 Participants' understandings about HIV in older age were remarkably similar.

371 Understandings offered by participants with HIV did not differ from those offered by

372 participants without HIV. Instead those with HIV challenged HIV-related stigma by  
373 differentiating themselves and their experiences from shared understandings (see Freeman  
374 2012).

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

### 385 *The sexual transmission of HIV*

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

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

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

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

403 [Doris, female, 70s, HIV+]

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

408 *I think that if that person took heed of advice given about AIDS they would not have*  
409 *been in that situation because each time we go to the hospital... we are sensitised*  
410 *about AIDS. Even on the radio - issues about AIDS are there.*

411 [Mercy, female, 50s, HIV-]

412 *The first thing that [my wife] told me [when I told her I had HIV] was 'that is what*  
413 *you wanted, because I knew you were doing chiwerewere. You were leaving me*  
414 *here, and going out to look for other women, because of this you have what you*  
415 *wanted'.*

416 [Daniel, male, early 50s, HIV+]

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

424 *When it's [HIV] found with a young person, they say 'let's put that aside'. They say*  
425 *with young people 'how could they keep themselves? They need to eat each other*  
426 *[have sex], that's nature'.*

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

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

430 [Youngson, male, 70, HIV-]

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

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

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

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

445 *I Who is talked about more?*

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

448 *[...]*

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

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

454 *I So you mean, being promiscuous? It’s fitting for young people?*

455 *R Yes*

456 *I And not you old people?*

457 *R Yes, it’s not our size. It’s not our size.*

458 [Nyuma, female, 68, HIV+]

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

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

472 [Winford, male, early 80s, HIV-]

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

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



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

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

515 [Rhoda, female, 56, HIV-]

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

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





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

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

564 [Mercy, female, 50s, HIV-]

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

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

574

[Stella, female, 70s, HIV+]

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

579

580 *HIV requires intensive caregiving*

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

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

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

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

602 [Rhoda, female, 56, HIV-]

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

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

613 [Patuma, female, 58, HIV-]

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

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

621 *To those who don't suffer from disease of AIDS, when they become sick, we bathe*  
622 *them. If it is me, children bath me, making me clean... But AIDS, people go*  
623 *disrespectfully. Disrespectfully. Everything, everything! [Points to imaginary*  
624 *food] ...Nothing remaining at home. Nothing!*

625 [Ruth, female, late 70s, HIV-]

## 626 **CONCLUSION**

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

635 Stigma-focused interventions should be grounded in knowledge of the source of stigma.

636 However stigma itself is rarely the unit of analysis in studies focusing on older populations.

637 Previous studies have tended to describe older adults' expectations of being stigmatised or

638 discriminated. This study is one of the first to conduct a detailed investigation of the

639 relationship between meanings of older age and HIV that underpin understandings of HIV in

640 older age as a discrediting attribute.

641 In Balaka, Malawi, these understandings centred on age- and HIV-related loss of the bodily,  
642 moral and social power required to produce one's membership of the social world through the  
643 performance of one's own survival and that one's kin. Older men and women frequently  
644 referred to those unable to work to secure this status of being and belonging as being "like  
645 children" (terminology also observed in Botswana (Guillette, 1992) and Kenya (Cattell,  
646 2002)). That work is important for building social relationships and attaining social power  
647 has been observed in a variety of African settings and historical periods (Englund, 1999;  
648 Alverson, 1978; Comaroff and Comaroff, 2001; Hammond and Jablow, 1976; Livingston,  
649 2002). Many of these studies have observed that older adults continue to work into very old  
650 age to prevent negative social labelling. For example, in a setting also dominated by  
651 agricultural production and familial support networks, Maria Cattell's ethnography of the  
652 Abaluyia in Kenya identifies the importance of being "active" and "useful". She notes how  
653 even the frailest older adults work in their fields and homes, observing that "it is their way of  
654 claiming full personhood and worthwhileness. To be considered or to feel useless calls into  
655 question one's value as *omundu* – a person, a human being" (Cattell, 2002: 170).

656 Ethnographic writings on the life course globally have frequently made a distinction between  
657 older adults in their productive prime and very old people, who are less productive and  
658 subsequently play marginal roles in society. The association between membership of the  
659 social world and productivity is reflected in the names that have been documented for this  
660 group: the "old-dead" among the !Kung/Ju/'hoansi of Botswana (Lee, 1992:43; Rosenberg,  
661 2009:32) and the "completely far gone" among the Akan of Ghana (Apt, 1995:17).

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

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

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

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

687 *Limitations and areas for future research*

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

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

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

706

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