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DOI:

[10.1080/09540121.2018.1465176](https://doi.org/10.1080/09540121.2018.1465176)

*Document Version*

Peer reviewed version

[Link to publication record in King's Research Portal](#)

*Citation for published version (APA):*

Lowther, K., Harding, R., Simms, V., Gikaara, N., Ahmed, A., Ali, Z., Kariuki, H., Sherr, L., Higginson, I. J., & Selman, L. (2018). Effect of participation in a randomised controlled trial of an integrated palliative care intervention on HIV-associated stigma. *AIDS Care - Psychological and Socio-Medical Aspects of AIDS/HIV*, 1-9. Advance online publication. <https://doi.org/10.1080/09540121.2018.1465176>

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1 **Effect of participation in a randomised controlled trial of an**  
2 **integrated palliative care intervention on HIV-associated stigma**

3

4 Short title/running head: Resistance to HIV-associated stigma

5 Word count 3599

## 6 Abstract

7 We conducted in Kenya a mixed-methods randomised controlled trial (RCT) of a  
8 nurse-led palliative care intervention integrated with anti-retroviral therapy (ART)  
9 provision for the management of HIV. Here we report qualitative findings showing  
10 increased resistance to HIV-associated stigma among trial participants. A mixed  
11 method design was chosen to enable identification of the active ingredients of the  
12 intervention and exploration of participants' experiences of receiving the intervention.  
13 The RCT was conducted from July 2011 to November 2012 in a community hospital  
14 in the city of Mombasa, Kenya, with a sample of 120 adults with HIV on ART. Thirty  
15 participants were purposively selected to take part in a qualitative exit interview,  
16 based on study arm and mental health outcome.

17 Inductive thematic analysis revealed increased resistance to HIV-associated stigma  
18 in both the intervention and control groups. Specifically, patients in both groups  
19 described benefit from the social support, compassionate care, and open and  
20 respectful communication they received through study participation. Participants  
21 described improved self-image, increased access to social agency, and increased  
22 resistance to HIV-associated stigma. Our findings suggest that there is potential to  
23 increase resistance to stigma through simple mechanisms of support, compassion,  
24 and improved communication in routine care. The self-reported impact of trial  
25 participation on stigma also has implications for future trials in populations in  
26 resource-constrained settings where stigma is common.

27

28 Keywords: HIV/AIDS; Stigma; Shame; Palliative Care; Kenya;

## 29 **Introduction**

30 Stigma was defined by Goffman in 1963 as a mark of social disgrace, where the  
31 stigmatised are excluded from social acceptance and are socially devalued  
32 (Goffman, 1963). Although commonly understood at the individual level (Herek,  
33 Saha, & Burack, 2013a), or the macro-societal level (Parker & Aggleton, 2003), an  
34 appreciation of both acknowledges how social processes become part of a  
35 stigmatised other's identity making resistance at an individual level very difficult  
36 (Catherine Campbell & Deacon, 2006). The persistence of HIV associated stigma, is  
37 a threat to progress in the control of HIV internationally (Stangl & Grossman, 2013), a  
38 barrier to testing (Dapaah & Senah, 2016), prevention of mother-to-child transmission  
39 (Turan & Nyblade, 2013), and, once diagnosis is confirmed, stigma remains a barrier to  
40 PLWH accessing adequate healthcare (Bogart et al., 2013; Dasgupta, Sullivan, Dasgupta,  
41 Saha, & Salazar, 2013). It is also associated with non-adherence to antiretroviral  
42 therapy (ART), increasing the risk of viral resistance (Mhode & Nyamhanga, 2016;  
43 Sweeney & Venable, 2016).

44 Community members often distance themselves from PLWH due to stigma (C.  
45 Campbell, Foulis, Maimane, & Sibiya, 2005; Visser & Sipsma, 2013), denying their own risk  
46 of contracting HIV, putting themselves at increased risk of transmission and delayed  
47 diagnosis (Nyblade et al., 2003). Among PLWH, the social ramifications of disclosure  
48 increase the risk of transmission through reluctance to openly take medications or  
49 negotiate condom use with a sexual partner (Mbonu, van den Borne, & De Vries, 2009;  
50 Turan & Nyblade, 2013).

51 In addition to these public health concerns, there is evidence that people  
52 experiencing HIV-associated stigma report less healthcare utilization, and poorer

53 physical health (Bennett, Traub, Mace, Juarascio, & O’Hayer, 2016; Herek, Saha, & Burack,  
54 2013b). HIV-associated stigma also manifests as social isolation and rejection (C.  
55 Campbell et al., 2005; Owolabi et al., 2012), increasing depression (Palmer et al., 2011;  
56 Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012), anxiety (Adewuya et al., 2009) and  
57 low self-esteem (Visser & Sipsma, 2013). A recent study suggests that this relationship  
58 between HIV-associated stigma and psychological well-being may be mutually  
59 reinforcing (Miller et al., 2016).

60 The international community struggles to identify stigma reduction interventions that  
61 are effective for HIV-related health outcomes (Stangl, Lloyd, M Brady, Holland, &  
62 Baral, 2013). Studies are often methodologically weak due to predominant use of  
63 locally-created and/or un-validated outcome measures, which inhibit interpretation  
64 and comparison across studies (Sengupta, Banks, Jonas, Miles, & Smith, 2011;  
65 Stangl et al., 2013).

66 HIV-associated stigma also presents high costs for society (direct and indirect effects  
67 of stigma reduction have been valued at a potential \$1000 per point on the Berger  
68 Stigma scale) (Brent, 2016).

69 We conducted a randomised controlled trial (RCT) of a nurse-led palliative care  
70 intervention for PLWH established on ART in Mombasa, Kenya (Lowther et al., 2012,  
71 2014, 2015). In qualitative exit interviews, the themes of stigma, resistance to stigma,  
72 and the effects of participation in the research, emerged inductively as highly salient  
73 to participants. In this paper, we aim to describe experiences of stigma and stigma  
74 resistance among PLWH enrolled in the trial, and to draw out implications for clinical  
75 practice and research.

## 76 **Materials and methods**

77 The Treatment Outcomes in Palliative Care (TOPCare) study was an RCT of a  
78 nurse-led, integrated palliative care intervention for HIV positive patients conducted  
79 in a clinic in Mombasa, Kenya. The trial had an embedded qualitative component  
80 with a sequential, explanatory design (Ivankova, Creswell, & Stick, 2006). Study  
81 methodology is reported elsewhere (Lowther et al., 2012), as are details of  
82 recruitment, follow up and missing data (Lowther et al., 2014), and results of the trial  
83 (Lowther et al., 2015). We found the intervention had significant positive effect in terms  
84 of mental health and well-being, but no effect on pain or physical outcomes (Lowther  
85 et al., 2015).

86 The intervention consisted of 4 months of palliative care integrated into patients'  
87 routine HIV outpatient care. It was delivered by two experienced HIV clinic nurses  
88 who received two weeks' specialist training in palliative care from the Kenyan  
89 Hospice and Palliative Care Association and clinical support and mentoring from  
90 local hospice nurses. The training covered pain management, symptom  
91 management, nutrition, psychosocial and spiritual assessment and care, breaking  
92 bad news, ethical and legal issues, and bereavement. Participants in the intervention  
93 arm received a minimum of 7 appointments (approximately 45 minutes long) with  
94 one of the two intervention nurses. The nurse delivered person-centred care which  
95 included a holistic assessment of emotional, spiritual, social and physical well-being,  
96 patients' understanding of HIV, and ability to maintain treatment adherence. This  
97 assessment informed care delivery, with hospice referral for complex cases of pain  
98 and symptom management. Control arm participants received standard care in the  
99 Comprehensive Care Clinic (CCC) at the study site, which consisted of monthly

100 appointments usually lasting 5-7 minutes. They were seen by HIV clinic nurses with  
101 similar levels of experience but without the additional training.

## 102 *Sampling*

103 Participants who met the inclusion criteria for the wider trial were aged  $\geq 18$ , HIV  
104 positive and on ART for more than one month, and reported moderate to severe pain  
105 or symptoms lasting at least 2 weeks, as measured by the African Palliative Care  
106 Association Palliative Outcome Scale (APCA POS (Harding et al., 2010)). The sub-  
107 sample recruited to the qualitative component of the study was purposively selected  
108 based on study arm allocation and individual quantitative response to participation in  
109 the trial. Participants from the intervention arm were over-sampled (10 control /20  
110 intervention) to enable in depth exploration of the active ingredients and mechanism  
111 of action of the intervention (data to be reported elsewhere). Sampling was in line  
112 with a sequential explanatory mixed methods design: we purposively selected  
113 participants to achieve a maximum variation sample based on individuals' clinical  
114 response to the intervention. Response was measured using the Medical Outcomes  
115 Survey – HIV Mental Health Summary Score (MOS-HIV MHSS), the mental health  
116 subscale of a well-validated, disease-specific quality of life measure (Wu, 1999). A  
117 change of 10 points on the MOS-HIV MHSS is considered clinically significant (Wu,  
118 1999). Participants were categorised as “improving” if they improved by  $\geq 10$  points  
119 during the four-month study period, “static” if there was  $< 10$  points change in either  
120 direction, and “deteriorating” if they decreased by  $> 10$  points over the study period.  
121 A sample size of thirty qualitative interviews was chosen to balance opportunity for  
122 data saturation with feasibility of in-depth analysis (Sandelowski, 1995).

123 *Data collection*

124 Data collection in both groups involved five quantitative data collection appointments  
125 at monthly intervals, with selected participants invited to take part in a qualitative  
126 interview from 1-8 months post trial exit.

127 The same Kenyan researcher (NG) who collected the quantitative data throughout  
128 the RCT conducted the qualitative exit interviews. The researcher was skilled and  
129 experienced in qualitative research, provided with study-specific training, and  
130 bilingual in English and Swahili. The interviews lasted approximately 45 minutes, and  
131 were guided by a semi-structured topic guide developed by the study group. The  
132 topic guide included questions about participants' physical, psychological, social and  
133 spiritual well-being before, during and after the study, in line with the holistic nature  
134 of the palliative care approach (WHO, 2013). Participants were also asked about their  
135 experiences of participating in the study, and, if allocated to the intervention arm,  
136 their perceptions of the differences between the two models of care (intervention vs  
137 standard care).

138 The interviews were conducted in a private location at the study site in either  
139 English, Swahili or both, depending on participant preference. Participants were  
140 welcomed into the study setting, and given refreshments to demonstrate hospitality  
141 and respect. The interviews were digitally recorded, transcribed and translated into  
142 English (where needed) by an experienced translator. Translations were quality  
143 checked by the researcher against the interview recordings, and amended if  
144 inaccuracies or errors were identified.



## 145 *Analysis*

146 Transcripts were analysed thematically using a combination of deductive and  
147 inductive coding (Braun & Clarke, 2006). Deductive themes were identified according  
148 to the domains of well-being integral to palliative care (physical, psychological, social  
149 and spiritual), while additional themes emerged inductively. Themes were defined as  
150 codes or collections of codes containing elements which represented a patterned  
151 response or concept (Barbour, 2013). Following Barbour, the following questions  
152 were posed to identify themes, with constant reference to the study objectives:  
153 “Which codes are repeated? How do they relate to each other? Do these codes  
154 relate as sub-themes or associates in that they occur simultaneously?” (Barbour,  
155 2013). Once identified, themes were organised hierarchically into major themes and  
156 sub-themes, according to their meaning and relationship to each other, to structure  
157 and reduce the volume of data. Major themes were those with high levels of salience  
158 and significance, in terms of understanding the therapeutic aspects of the  
159 intervention and their repetition across the dataset. Analysis was managed using  
160 NVivo 9 software. Findings are presented using anonymised illustrative quotes,  
161 annotated with the participant’s gender, age and intervention arm (Tables 2 and 3,  
162 cross-referenced in the text).

## 163 *Ethics*

164 Ethical approval was provided by King’s College London Research Ethics Committee  
165 (BDM/10/11-31) and the Kenyan Medical Research Institute (KEMRI/RES/7/3/1). All  
166 patients gave written informed consent (if the participant was unable to read or write,  
167 the information sheet was read aloud and a thumb print given to indicate consent).

168 **Results**

169 *Sample characteristics*

170 30 participants were interviewed; no one approached declined. Participants were  
171 similar to the wider trial sample in terms of clinical and demographic characteristics  
172 (Table 1). Mean age was 39.1, with a mean of 2.4 children and 3.2 financial  
173 dependants. Most were women (80%, n=24), and two-thirds (67.7%, n=20)  
174 completed primary school as their highest educational attainment. Interviews were  
175 conducted from one to eight months after trial exit (mean 4.2 months). The research  
176 team judged that data saturation was reached in that no new themes emerged from  
177 the analysis of later interviews.

178 [INSERT TABLE 1 NEAR HERE]

179 *Findings*

180 Stigma arose inductively in the data as an important characteristic of participants'  
181 experience of living with HIV, described by 25 of the 30 participants. Findings  
182 regarding stigma are presented in two themes: experience of HIV-associated stigma,  
183 and effects on HIV-associated stigma of participation in the trial.

184 *Experience of HIV-associated stigma (Table 2)*

185 When asked to describe their well-being before study participation, many participants  
186 described the experience of stigma indirectly, in terms of a fear of disclosure of their  
187 HIV diagnosis. They anticipated that this would lead to being shamed, socially  
188 isolated or discriminated against (quote 1). Participants reported hiding their status  
189 behind diagnoses which were more socially acceptable to their networks, for  
190 example saying they had tuberculosis (TB). The HIV positive diagnosis led some

191 participants to self-hatred and suicidal ideation. One participant described how  
192 internalised stigma, from cultural norms associating HIV with immorality, created an  
193 identity crisis (quote 2). Once they disclosed their HIV status to others, some  
194 participants reported experiencing anger and blame from their families and other  
195 community members (quote 3).

196 Experiencing this enacted stigma or discrimination against PLWH, either directly or  
197 vicariously, discouraged participants from disclosing their status, which led to  
198 increased isolation and suffering. Social isolation was a major cause of sadness;  
199 friends from before they were diagnosed had left, increasing their sense of  
200 vulnerability and isolation (quote 4)

201 [INSERT TABLE 2 NEAR HERE]

202 *Effects of participation in research on HIV-associated stigma (Table 3)*

203 During the counselling received in clinical appointments, intervention participants  
204 were encouraged by the study nurses to see themselves as normal, just like any  
205 other person. This was reported to improve self-esteem, self-image and acceptance,  
206 and help participants resist internalised stigma (quotes 5-7). Some intervention arm  
207 participants described dramatic changes in their outlook, from suicidal to positive  
208 (quote 8). However, the beneficial effects of participation also extended to those  
209 PLWH in the control arm, with both groups of participants describing the therapeutic  
210 effects of their interactions with the study team (quotes 9, 10)

211 Participants built a trusting relationship with the researcher who administered the  
212 study questionnaires, owing to the compassion they witnessed, and her non-  
213 judgemental and open communication style. They described how this way they were  
214 treated, enabled them to rebuild a positive self-image (quotes 11, 12). This change in

215 self-regard was often described as a shift in seeing themselves as normal rather  
216 than abnormal, and worthy of respect, social interest and engagement (quotes 13,  
217 14). Participants described how, through this growth in self-esteem, they were more  
218 able to reject stigmatising messages, and became confident in disclosing their HIV  
219 positive status to their close communities (quote 15). Being treated as a normal  
220 person by a health care practitioner was in stark contrast to the advice received by  
221 one participant attending the standard clinic, who reported she was advised to  
222 'behave normally' when she received her diagnosis, in case people realised that she  
223 was HIV positive (quote 16).

224 One of the most powerful aspects of participation in reducing internalised stigma was  
225 being given the space and permission to talk (quotes 17, 18). Some participants  
226 clearly attributed the effect to the process of completing the outcome measurements  
227 (quotes 19, 20). Because of participation in the study and the support they received  
228 through attending data collection appointments, some participants made concrete  
229 changes to their social situations (quote 21). Others became activists in less public  
230 ways, making themselves available to others for counselling and support, particularly  
231 those who had recently received their diagnosis. They described having the  
232 confidence and self-belief to act normally, interacting with their communities  
233 accordingly, and ignoring the stigmatising responses they had previously anticipated  
234 and feared. These newly created identities as 'activists' were socially acceptable and  
235 added purpose to participants' lives participants (quotes 22, 23).

236 [INSERT TABLE 3 NEAR HERE]

## 237 **Discussion**

238 The findings of this study demonstrate the therapeutic value of a relationship  
239 characterised by compassionate care, social support, and open and non-  
240 judgemental communication. While intervention group participants described benefit  
241 from their appointments with the study nurse, participants in both groups described  
242 the way that simply participating in the trial's data collection procedures helped them  
243 to increase their resistance to the stigma associated with HIV.

244 The researcher completed standardised patient reported outcome measures with  
245 each participant at regular intervals over a four-month time-period. She had no  
246 therapeutic remit or training, yet participants clearly described therapeutic benefit,  
247 including increasing ability to resist stigma. We can see two possible reasons for  
248 this. Firstly, the act of being asked questions about their well-being and problems  
249 may have served to acknowledge their importance. Secondly, being accepted and  
250 treated with respect may have helped patients renegotiate a positive self-identity.

251 This second hypothesis is supported by other studies of HIV-associated stigma  
252 (Goudge, Ngoma, Manderson, & Schneider, 2009; Soskolne, 2003). In a study in South  
253 Africa, women living with HIV described how, given time, they were able to negotiate  
254 a new positive self-identity which helped them cope with anxiety and the stigma of  
255 their HIV diagnosis (Soskolne, 2003). The work of Goudge et al. (2009) describes the  
256 crucial role of social support – the very thing lacking when stigma is present and  
257 powerful - in this process (Goudge et al., 2009). They found that through social  
258 support, PLWH were able to express their emotions, make sense of their diagnosis  
259 and move towards a problem-solving approach toward managing their health,

260 whereas those with less support were less able to adjust and cope (Goudge et al.,  
261 2009).

262 The shift observed in our participant group can also be understood through the lens  
263 of shame and shame resistance theories. Van Vliet's theory of shame resistance  
264 states that to improve the affected person's self-concept individuals must undergo a  
265 process of reconstruction, rebuilding a new identity in response to a shaming  
266 experience (Van Vliet, 2008). She describes the five sub-processes this involves:  
267 connecting, refocusing, accepting, understanding and resisting (Van Vliet, 2008).  
268 These sub-processes appear to mirror our participants' descriptions of their  
269 experience of participating in the trial. Connecting and refocusing are described  
270 when patients talk of the social support they received from the research team.  
271 Acceptance can be seen in their descriptions of learning to accommodate their HIV  
272 status, in part through the acceptance they experienced from the research team.  
273 Participants receiving the intervention described being treated as normal people, told  
274 that they were normal and advised that should treat themselves accordingly, as  
275 particularly potent aspects of the intervention. Central to acceptance was coming to  
276 understand that anyone, even morally 'good' people, can get HIV. The final sub-  
277 process in Van Vliet's theory is resistance. Using their reformed identity and renewed  
278 positive self-image as 'good' or 'normal' people, some participants expressed stigma  
279 resistance through becoming an activist or supporter of other PLWH. Others  
280 expressed their resistance through reaching out to rejecting family members,  
281 deciding not to be ashamed, and widely disclosing their HIV status.

282 Our findings regarding reforming identity reflect those of Aujoulat et al.'s study  
283 (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008), in which chronically ill

284 patients described a process through which they managed to resolve their identities  
285 as 'people living with a disease', not as 'diseased people'. Aujoulat et al. describe the  
286 processes through which individuals come to terms with a disrupted 'well' or 'normal'  
287 identity, manage the threat to their security and identity which illness represents, and  
288 face the lack of coherence or meaning which often accompanies diagnosis (Aujoulat  
289 et al., 2008). This reflects our own data and the wider HIV literature, which highlights  
290 that resistance for PLWH involves re-negotiating control over health and illness  
291 (Brinsdon, Abel, & Desrosiers, 2017; Goudge et al., 2009).

292 Our findings suggest that healthcare systems can play a role both in perpetuating  
293 and alleviating HIV-associated stigma. Research from South Africa also describes  
294 how women attending health care settings appreciated positive interactions with  
295 staff, while negative experiences further stigmatised (Okoror, BeLue, Zungu, Adam,  
296 & Airhihenbuwa, 2014). Recent research from Bangladesh demonstrates how a  
297 sexual and reproductive health rights training package administered to health care  
298 workers can reduce the stigma experienced by their patients. This study found that  
299 indicators of HIV-associated stigma among healthcare workers were reduced,  
300 alongside an increase in patient satisfaction with services (Geibel et al., 2017). In our  
301 study, the participants witnessed a working example of supportive, stigma-free care,  
302 and help to manage stigma through the provision of space to disclose and discuss  
303 openly.

304 An alternative explanation for the shift we observed in how participants felt could be  
305 that participants adjusted to their diagnosis over time. However, this sample of  
306 participants had been diagnosed with HIV for a median of 3.5 years (IQR 1.3-5.2)  
307 and had been on ART for a median of 2.5 years (IQR 0.8-4.2), therefore it is unlikely  
308 that this is the sole explanation. It might also be that the intervention itself, rather

309 than trial participation, improved stigma resistance. However, the striking similarity  
310 between the changes described by both control and intervention arm participants  
311 suggests otherwise. There was no contamination in the trial; control arm participants  
312 were seen by different clinical nurses. Additionally, the participants repeatedly  
313 referred to 'you' (addressing the researcher) as the one who had helped them.

314 A limitation of the study is that the concept of stigma emerged as an inductive theme  
315 during data analysis rather than being explored explicitly in the topic guides. Data on  
316 the experience of stigma and response to stigma was therefore not collected from all  
317 participants. However, despite this, stigma was a key feature of many patients'  
318 experiences of trial participation, described by 25 of the 30 participants. Another  
319 limitation is that, due to the inclusion criteria for the wider trial, the findings represent  
320 the experiences of PLWH who have been on ART for more than a month and are  
321 experiencing non-acute moderate to severe pain or other symptoms. However, this  
322 does not negate the importance of the experiences of this patient group. Since  
323 interviews were conducted by the same researcher who implemented the study,  
324 some social desirability bias is possible. We chose to keep the same researcher for  
325 both study components because of her experience and skill in conducting palliative  
326 care research, as we believe this skill outweighed any potential bias. Finally, the  
327 qualitative interviews necessarily took place after the trial had finished and so could  
328 be affected by recall bias.

329 Our findings have direct implications for clinical care and research for HIV  
330 communities, highlighting the association between psychosocial care and increased  
331 resistance to HIV-associated stigma. Failing to tackle stigma is a significant threat to  
332 infection control, access to testing, adequate treatment, and healthcare utilisation.  
333 Stakeholders at all levels of HIV care provision should consider the potential effects



334 of increasing levels of compassion, communication and social support in the care  
335 they provide to help PLWH resist stigma. It may be possible to integrate this  
336 approach into other, more established roles that are included in recommendations  
337 for best practice, such as treatment navigators or peer educators (Simoni,  
338 Pantalone, Plummer, & Huang, 2007; Thompson et al., 2012).

339 Future research is needed to explore whether the hypothesised shame resistance  
340 mechanisms of connecting, refocusing, accepting, understanding and resisting do  
341 indeed contribute to stigma resistance in PLWHA. Stigma should also be measured  
342 using a standardised outcome measure such as the PLWH Stigma Index, adapted  
343 and validated in each cultural setting, to enable cross-study and cross-country  
344 comparison and service evaluation (dos Santos, Kruger, Mellors, Wolvaardt, & van der  
345 Ryst, 2014; International Planned Parenthood Federation, 2008).

346 The findings also have implications for researchers working with socially isolated or  
347 stigmatised groups, who should consider the beneficial effects of participating in  
348 research, which may be in addition to any overt therapeutic input, in study design.  
349 This has been discussed more fully elsewhere (Lowther et al., 2016).

350 Resistance to HIV-associated stigma is possible, and can be encouraged through  
351 compassionate communication and social support. If these findings can be replicated  
352 at a larger scale and in different contexts, this affordable and life-affirming approach  
353 could have considerable public health and clinical significance for management of  
354 the HIV pandemic.

### 355 *Funding*

356 This work was supported by the Diana Princess of Wales Memorial Fund.

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