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

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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 ≥ 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 ≥ 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.

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