



Lowther, K., Harding, R., Simms, V., Gikaara, N., Ahmed, A., Ali, Z., ... Selman, L. (2018). Effect of participation in a randomised controlled trial of an integrated palliative care intervention on HIV-associated stigma. *AIDS Care*. <https://doi.org/10.1080/09540121.2018.1465176>

Peer reviewed version

Link to published version (if available):
[10.1080/09540121.2018.1465176](https://doi.org/10.1080/09540121.2018.1465176)

[Link to publication record in Explore Bristol Research](#)
PDF-document

This is the author accepted manuscript (AAM). The final published version (version of record) is available online via Taylor and Francis at <https://www.tandfonline.com/doi/full/10.1080/09540121.2018.1465176>. Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research

General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available:
<http://www.bristol.ac.uk/pure/about/ebr-terms>

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

3

4 Authors:

5 **Keira LOWTHER (PhD)** (Corresponding author)

6 Department of Palliative Care and Rehabilitation, King's College London, Cicely
7 Saunders Institute, Bessemer Road, SE5 9PJ, UK.

8 Keira.Lowther@dartington.org.uk

9 +44 (0) 207 848 5518

10 **Richard HARDING (PhD)**

11 King's College London, Cicely Saunders Institute, Department of Palliative Care and
12 Rehabilitation, Bessemer Road, SE5 9PJ, UK.

13 **Victoria SIMMS (PhD)**

14 London School of Hygiene and Tropical Medicine, London, Keppel Street, London,
15 WC1E 7HT. UK.

16 **Nancy GIKAARA (BA)**

17 Kenyan Hospice Palliative Care Association, Nairobi, Kenya, P.O Box 20854, 00202,
18 Nairobi, Kenya.

19 **Aabid AHMED (MD)**

20 Bomu Hospital, Off Airport Road, Soweto, P.O. BOX 95683, Mombasa, Kenya.

21 **Zipporah ALI (MD)**

22 Kenya Hospices and Palliative Care Association, P.O Box 20854, 00202, Nairobi

23 **Hellen KARIUKI (PhD)**

24 University of Nairobi, Department of Medical Physiology, Chiromo Campus, PO BOX
25 30197 (00100) Nairobi, Kenya.

26 **Lorraine SHERR (PhD)**

27 University College London, Dept of Infection and Population Health, Rowland Hill
28 Street, London NW32PF, UK

29 **Irene J HIGGINSON (PhD)**

30 King's College London, Cicely Saunders Institute, Department of Palliative Care and
31 Rehabilitation, Bessemer Road, SE59PJ, UK.

32 **Lucy SELMAN (PhD)**

33 Population Health Sciences, Bristol Medical School, University of Bristol, Whatley
34 Road, Bristol BS8 2PS. UK.

35 *corresponding author

36

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

38 Word count 3599

39 **Abstract**

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

50 Inductive thematic analysis revealed increased resistance to HIV-associated stigma
51 in both the intervention and control groups. Specifically, patients in both groups
52 described benefit from the social support, compassionate care, and open and
53 respectful communication they received through study participation. Participants
54 described improved self-image, increased access to social agency, and increased
55 resistance to HIV-associated stigma. Our findings suggest that there is potential to
56 increase resistance to stigma through simple mechanisms of support, compassion,
57 and improved communication in routine care. The self-reported impact of trial
58 participation on stigma also has implications for future trials in populations in
59 resource-constrained settings where stigma is common.

60

61 **Keywords:** HIV/AIDS; Stigma; Shame; Palliative Care; Kenya;

62 **Introduction**

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

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

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

86 physical health (Bennett, Traub, Mace, Juarascio, & O’Hayer, 2016; Herek, Saha, & Burack,
87 2013b). HIV-associated stigma also manifests as social isolation and rejection (C.
88 Campbell et al., 2005; Owolabi et al., 2012), increasing depression (Palmer et al., 2011;
89 Sumari-de Boer, Sprangers, Prins, & Nieuwkerk, 2012), anxiety (Adewuya et al., 2009) and
90 low self-esteem (Visser & Sipsma, 2013). A recent study suggests that this relationship
91 between HIV-associated stigma and psychological well-being may be mutually
92 reinforcing (Miller et al., 2016).

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

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

102 We conducted a randomised controlled trial (RCT) of a nurse-led palliative care
103 intervention for PLWH established on ART in Mombasa, Kenya (Lowther et al., 2012,
104 2014, 2015). In qualitative exit interviews, the themes of stigma, resistance to stigma,
105 and the effects of participation in the research, emerged inductively as highly salient
106 to participants. In this paper, we aim to describe experiences of stigma and stigma
107 resistance among PLWH enrolled in the trial, and to draw out implications for clinical
108 practice and research.

109 **Materials and methods**

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

119 The intervention consisted of 4 months of palliative care integrated into patients'
120 routine HIV outpatient care. It was delivered by two experienced HIV clinic nurses
121 who received two weeks' specialist training in palliative care from the Kenyan
122 Hospice and Palliative Care Association and clinical support and mentoring from
123 local hospice nurses. The training covered pain management, symptom
124 management, nutrition, psychosocial and spiritual assessment and care, breaking
125 bad news, ethical and legal issues, and bereavement. Participants in the intervention
126 arm received a minimum of 7 appointments (approximately 45 minutes long) with
127 one of the two intervention nurses. The nurse delivered person-centred care which
128 included a holistic assessment of emotional, spiritual, social and physical well-being,
129 patients' understanding of HIV, and ability to maintain treatment adherence. This
130 assessment informed care delivery, with hospice referral for complex cases of pain
131 and symptom management. Control arm participants received standard care in the
132 Comprehensive Care Clinic (CCC) at the study site, which consisted of monthly

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

135 *Sampling*

136 Participants who met the inclusion criteria for the wider trial were aged ≥ 18 , HIV
137 positive and on ART for more than one month, and reported moderate to severe pain
138 or symptoms lasting at least 2 weeks, as measured by the African Palliative Care
139 Association Palliative Outcome Scale (APCA POS (Harding et al., 2010)). The sub-
140 sample recruited to the qualitative component of the study was purposively selected
141 based on study arm allocation and individual quantitative response to participation in
142 the trial. Participants from the intervention arm were over-sampled (10 control /20
143 intervention) to enable in depth exploration of the active ingredients and mechanism
144 of action of the intervention (data to be reported elsewhere). Sampling was in line
145 with a sequential explanatory mixed methods design: we purposively selected
146 participants to achieve a maximum variation sample based on individuals' clinical
147 response to the intervention. Response was measured using the Medical Outcomes
148 Survey – HIV Mental Health Summary Score (MOS-HIV MHSS), the mental health
149 subscale of a well-validated, disease-specific quality of life measure (Wu, 1999). A
150 change of 10 points on the MOS-HIV MHSS is considered clinically significant (Wu,
151 1999). Participants were categorised as “improving” if they improved by ≥ 10 points
152 during the four-month study period, “static” if there was < 10 points change in either
153 direction, and “deteriorating” if they decreased by > 10 points over the study period.
154 A sample size of thirty qualitative interviews was chosen to balance opportunity for
155 data saturation with feasibility of in-depth analysis (Sandelowski, 1995).

156 *Data collection*

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

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

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

178 *Analysis*

179 Transcripts were analysed thematically using a combination of deductive and
180 inductive coding (Braun & Clarke, 2006). Deductive themes were identified according
181 to the domains of well-being integral to palliative care (physical, psychological, social
182 and spiritual), while additional themes emerged inductively. Themes were defined as
183 codes or collections of codes containing elements which represented a patterned
184 response or concept (Barbour, 2013). Following Barbour, the following questions
185 were posed to identify themes, with constant reference to the study objectives:
186 “Which codes are repeated? How do they relate to each other? Do these codes
187 relate as sub-themes or associates in that they occur simultaneously?” (Barbour,
188 2013). Once identified, themes were organised hierarchically into major themes and
189 sub-themes, according to their meaning and relationship to each other, to structure
190 and reduce the volume of data. Major themes were those with high levels of salience
191 and significance, in terms of understanding the therapeutic aspects of the
192 intervention and their repetition across the dataset. Analysis was managed using
193 NVivo 9 software. Findings are presented using anonymised illustrative quotes,
194 annotated with the participant’s gender, age and intervention arm (Tables 2 and 3,
195 cross-referenced in the text).

196 *Ethics*

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

201 **Results**

202 *Sample characteristics*

203 30 participants were interviewed; no one approached declined. Participants were
204 similar to the wider trial sample in terms of clinical and demographic characteristics
205 (Table 1). Mean age was 39.1, with a mean of 2.4 children and 3.2 financial
206 dependants. Most were women (80%, n=24), and two-thirds (67.7%, n=20)
207 completed primary school as their highest educational attainment. Interviews were
208 conducted from one to eight months after trial exit (mean 4.2 months). The research
209 team judged that data saturation was reached in that no new themes emerged from
210 the analysis of later interviews.

211 [INSERT TABLE 1 NEAR HERE]

212 *Findings*

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

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

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

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

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

234 [INSERT TABLE 2 NEAR HERE]

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

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

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

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

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

269 [INSERT TABLE 3 NEAR HERE]

270 **Discussion**

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

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

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

293 whereas those with less support were less able to adjust and cope (Goudge et al.,
294 2009).

295 The shift observed in our participant group can also be understood through the lens
296 of shame and shame resistance theories. Van Vliet's theory of shame resistance
297 states that to improve the affected person's self-concept individuals must undergo a
298 process of reconstruction, rebuilding a new identity in response to a shaming
299 experience (Van Vliet, 2008). She describes the five sub-processes this involves:
300 connecting, refocusing, accepting, understanding and resisting (Van Vliet, 2008).
301 These sub-processes appear to mirror our participants' descriptions of their
302 experience of participating in the trial. Connecting and refocusing are described
303 when patients talk of the social support they received from the research team.
304 Acceptance can be seen in their descriptions of learning to accommodate their HIV
305 status, in part through the acceptance they experienced from the research team.
306 Participants receiving the intervention described being treated as normal people, told
307 that they were normal and advised that should treat themselves accordingly, as
308 particularly potent aspects of the intervention. Central to acceptance was coming to
309 understand that anyone, even morally 'good' people, can get HIV. The final sub-
310 process in Van Vliet's theory is resistance. Using their reformed identity and renewed
311 positive self-image as 'good' or 'normal' people, some participants expressed stigma
312 resistance through becoming an activist or supporter of other PLWH. Others
313 expressed their resistance through reaching out to rejecting family members,
314 deciding not to be ashamed, and widely disclosing their HIV status.

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

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

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

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

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

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

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

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

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

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

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

388 *Funding*

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

390 **References:**

- 391 Adewuya, A. O., Afolabi, M. O., Ola, B. A., Ogundele, O. A., Ajibare, A. O., Oladipo,
392 B. F., & Fakande, I. (2009). Post-traumatic stress disorder (PTSD) after
393 stigma related events in HIV infected individuals in Nigeria. *Social Psychiatry
394 and Psychiatric Epidemiology*, 44(9), 761–766.
395 <https://doi.org/10.1007/s00127-009-0493-7>
- 396 Aujoulat, I., Marcolongo, R., Bonadiman, L., & Deccache, A. (2008). Reconsidering
397 patient empowerment in chronic illness: A critique of models of self-efficacy
398 and bodily control. *Social Science & Medicine*, 66(5), 1228–1239.
399 <https://doi.org/10.1016/j.socscimed.2007.11.034>
- 400 Barbour, R. (2013). *Introducing Qualitative Research: A Student's Guide*. SAGE.
- 401 Bennett, D. S., Traub, K., Mace, L., Juarascio, A., & O'Hayer, C. V. (2016). Shame
402 among people living with HIV: a literature review. *AIDS Care*, 28(1), 87–91.
403 <https://doi.org/10.1080/09540121.2015.1066749>
- 404 Bogart, L. M., Chetty, S., Giddy, J., Sypek, A., Sticklor, L., Walensky, R. P., ...
405 Bassett, I. V. (2013). Barriers to care among people living with HIV in South
406 Africa: Contrasts between patient and healthcare provider perspectives. *AIDS
407 Care*, 25(7), 843–853. <https://doi.org/10.1080/09540121.2012.729808>
- 408 Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative
409 Research in Psychology*, 3, 77–101.
- 410 Brent, R. J. (2016). The value of reducing HIV stigma. *Social Science & Medicine*,
411 151, 233–240. <https://doi.org/10.1016/j.socscimed.2016.01.014>
- 412 Brinsdon, A., Abel, G., & Desrosiers, J. (2017). 'I'm taking control': how people living
413 with HIV/AIDS manage stigma in health interactions. *AIDS Care*, 29(2), 185–
414 188. <https://doi.org/10.1080/09540121.2016.1204420>

415 Campbell, C., & Deacon, H. (2006). Unravelling the contexts of stigma: from
416 internalisation to resistance to change. *Journal of Community & Applied*
417 *Social Psychology, 16*(6), 411–417.

418 Campbell, C., Foulis, C. A., Maimane, S., & Sibiyi, Z. (2005). ‘I have an evil child at
419 my house’: stigma and HIV/AIDS management in a South African community.
420 *Am J Public Health, 95*(5), 808–15. <https://doi.org/10.2105/ajph.2003.037499>

421 Dapaah, J. M., & Senah, K. A. (2016). HIV/AIDS clients, privacy and confidentiality;
422 the case of two health centres in the Ashanti Region of Ghana. *BMC Medical*
423 *Ethics, 17*, 41. <https://doi.org/10.1186/s12910-016-0123-3>

424 Dasgupta, S., Sullivan, P. S., Dasgupta, A., Saha, B., & Salazar, L. F. (2013). Stigma
425 and access to HIV care among HIV-infected women in Kolkata, West Bengal.
426 *Journal of the International Association of Providers of AIDS Care, 12*(1), 44–
427 49. <https://doi.org/http://dx.doi.org/10.1177/1545109711401410>

428 dos Santos, M. M., Kruger, P., Mellors, S. E., Wolvaardt, G., & van der Ryst, E.
429 (2014). An exploratory survey measuring stigma and discrimination
430 experienced by people living with HIV/AIDS in South Africa: the people living
431 with HIV stigma index. *BMC Public Health, 14*(1), 80.

432 Geibel, S., Hossain, S. M. I., Pulerwitz, J., Sultana, N., Hossain, T., Roy, S., ... Yam,
433 E. (2017). Stigma Reduction Training Improves Healthcare Provider Attitudes
434 Toward, and Experiences of, Young Marginalized People in Bangladesh.
435 *Journal of Adolescent Health, 60*(2, Supplement 2), S35–S44.
436 <https://doi.org/10.1016/j.jadohealth.2016.09.026>

437 Goffman, E. (1963). *Stigma. Notes on the management of spoiled identity*. New
438 Jersey, USA: Prentice-Hall.

439 Goudge, J., Ngoma, B., Manderson, L., & Schneider, H. (2009). Stigma, identity and
440 resistance among people living with HIV in South Africa. *SAHARA J*, 6(3), 94–
441 104.

442 Harding, R., Selman, L., Agupio, G., Dinat, N., Downing, J., Gwyther, L., ...
443 Higginson, I. J. (2010). Validation of a core outcome measure for palliative
444 care in Africa: the APCA African Palliative Outcome Scale. *Health & Quality of*
445 *Life Outcomes*, 8, 10. <https://doi.org/10.1186/1477-7525-8-10>

446 Herek, G. M., Saha, S., & Burack, J. (2013a). Stigma and Psychological Distress in
447 People With HIV/AIDS. *Basic and Applied Social Psychology*, 35(1), 41–54.
448 <https://doi.org/10.1080/01973533.2012.746606>

449 Herek, G. M., Saha, S., & Burack, J. (2013b). Stigma and Psychological Distress in
450 People With HIV/AIDS. *Basic and Applied Social Psychology*, 35(1), 41–54.
451 <https://doi.org/10.1080/01973533.2012.746606>

452 International Planned Parenthood Federation, U. (2008). *The people living with HIV*
453 *stigma index*. London: IPPF. Retrieved from
454 [http://www.stigmaindex.org/90/publications/the-people-living-with-hiv-stigma-](http://www.stigmaindex.org/90/publications/the-people-living-with-hiv-stigma-index-user-guide.html)
455 [index-user-guide.html](http://www.stigmaindex.org/90/publications/the-people-living-with-hiv-stigma-index-user-guide.html)

456 Ivankova, N. V., Creswell, J. W., & Stick, S. L. (2006). Using Mixed-Methods
457 Sequential Explanatory Design: From Theory to Practice. *Field Methods*,
458 18(1), 3–20. <https://doi.org/10.1177/1525822X05282260>

459 Lowther, K., Harding, R., Ahmed, A., Gikaara, N., Ali, Z., Kariuki, H., ... Selman, L.
460 (2016). Conducting experimental research in marginalised populations:
461 clinical and methodological implications from a mixed-methods randomised
462 controlled trial in Kenya. *AIDS Care*, 28(sup1), 60–63.
463 <https://doi.org/10.1080/09540121.2016.1146214>

464 Lowther, K., Higginson, I. J., Simms, V., Gikaara, N., Ahmed, A., Ali, Z., ... Harding,
465 R. (2014). A randomised controlled trial to assess the effectiveness of a
466 nurse-led palliative care intervention for HIV positive patients on antiretroviral
467 therapy: recruitment, refusal, randomisation and missing data. *BMC Research*
468 *Notes*, 7(1), 600. <https://doi.org/10.1186/1756-0500-7-600>

469 Lowther, K., Selman, L., Simms, V., Gikaara, N., Ahmed, A., Ali, Z., ... Harding, R.
470 (2015). Nurse-led palliative care for HIV-positive patients taking antiretroviral
471 therapy in Kenya: a randomised controlled trial. *The Lancet HIV*, 2(8), e328–
472 e334. [https://doi.org/10.1016/S2352-3018\(15\)00111-3](https://doi.org/10.1016/S2352-3018(15)00111-3)

473 Lowther, K., Simms, V., Selman, L., Sherr, L., Gwyther, L., Kariuki, H., ... Harding,
474 R. (2012). Treatment outcomes in palliative care: the TOPCare study. A
475 mixed methods phase III randomised controlled trial to assess the
476 effectiveness of a nurse-led palliative care intervention for HIV positive
477 patients on antiretroviral therapy. *BMC Infectious Diseases*, 12, 288.
478 <https://doi.org/10.1186/1471-2334-12-288>

479 Mbonu, N. C., van den Borne, B., & De Vries, N. K. (2009). Stigma of people with
480 HIV/AIDS in Sub-Saharan Africa: a literature review. *Journal of Tropical*
481 *Medicine*, 2009.

482 Mhode, M., & Nyamhanga, T. (2016). Experiences and Impact of Stigma and
483 Discrimination among People on Antiretroviral Therapy in Dar es Salaam: A
484 Qualitative Perspective. *AIDS Research and Treatment*, 2016, e7925052.
485 <https://doi.org/10.1155/2016/7925052>

486 Miller, C. T., Solomon, S. E., Varni, S. E., Hodge, J. J., Knapp, F. A., & Bunn, J. Y.
487 (2016). A transactional approach to relationships over time between perceived
488 HIV stigma and the psychological and physical well-being of people with HIV.

489 *Social Science & Medicine*, 162, 97–105.
490 <https://doi.org/10.1016/j.socscimed.2016.06.025>

491 Nyblade, L., Pande, R., Mathur, S., MacQuarrie, K., Kidd, R., Banteyerga, H., ...
492 Bond, V. (2003). Disentangling HIV and AIDS stigma in Ethiopia, Tanzania
493 and Zambia.

494 Okoror, T. A., BeLue, R., Zungu, N., Adam, A. M., & Airhihenbuwa, C. O. (2014). HIV
495 Positive Women's Perceptions of Stigma in Health Care Settings in Western
496 Cape, South Africa. *Health Care for Women International*, 35(1), 27–49.
497 <https://doi.org/10.1080/07399332.2012.736566>

498 Owolabi, R. S., Araoye, M. O., Osagbemi, G. K., Odeigah, L., Ogundiran, A., &
499 Hussain, N. A. (2012). Assessment of stigma and discrimination experienced
500 by people living with HIV and AIDS receiving care/treatment in University of
501 Ilorin Teaching Hospital (UITH), Ilorin, Nigeria. *Journal of the International*
502 *Association of Physicians in AIDS Care*, 11(2), 121–127.
503 <https://doi.org/http://dx.doi.org/10.1177/1545109711399443>

504 Palmer, A. K., Duncan, K. C., Ayalew, B., Zhang, W., Tzemis, D., Lima, V., ... Hogg,
505 R. S. (2011). 'The way I see it': the effect of stigma and depression on self-
506 perceived body image among HIV-positive individuals on treatment in British
507 Columbia, Canada. *AIDS Care*, 23(11), 1456–66.
508 <https://doi.org/http://dx.doi.org/10.1080/09540121.2011.565021>

509 Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a
510 conceptual framework and implications for action. *Soc Sci Med*, 57(1), 13–24.

511 Sandelowski, M. (1995). Sample size in qualitative research. *Research in Nursing &*
512 *Health*, 18(2), 179–183.

513 Sengupta, S., Banks, B., Jonas, D., Miles, M. S., & Smith, G. C. (2011). HIV
514 interventions to reduce HIV/AIDS stigma: a systematic review. *AIDS Behav*,
515 15(6), 1075–87. <https://doi.org/10.1007/s10461-010-9847-0>

516 Simoni, J. M., Pantalone, D. W., Plummer, M. D., & Huang, B. (2007). A
517 Randomized Controlled Trial of a Peer Support Intervention Targeting
518 Antiretroviral Medication Adherence and Depressive Symptomatology in HIV-
519 Positive Men and Women. *Health Psychology*, 26(4), 488–495.
520 <https://doi.org/http://dx.doi.org/10.1037/0278-6133.26.4.488>

521 Soskolne, T. (2003). *Moving beyond the margins: A narrative analysis of the life*
522 *stories of women living with HIV/AIDS in Khayelitsha* (Report No. CSSR
523 Working Paper No. 33). Centre for Social Research, University of Cape Town.
524 Retrieved from <http://www.uct.ac.za/depts/cssr/pubs.html>

525 Stangl, A. L., & Grossman, C. I. (2013). Global Action to reduce HIV stigma and
526 discrimination. *Journal of the International AIDS Society*, 16(3Suppl 2).

527 Stangl, A. L., Lloyd, J. K., M Brady, L., Holland, C. E., & Baral, S. (2013). A
528 systematic review of interventions to reduce HIV-related stigma and
529 discrimination from 2002 to 2013: how far have we come? *Journal of the*
530 *International AIDS Society*, 16(3(Suppl 2)).
531 <https://doi.org/10.7448/IAS.16.3.18734>

532 Sumari-de Boer, I., Sprangers, M. A., Prins, J. M., & Nieuwkerk, P. T. (2012). HIV
533 stigma and depressive symptoms are related to adherence and virological
534 response to antiretroviral treatment among immigrant and indigenous HIV
535 infected patients. *AIDS and Behavior*, 16(6), 1681–1689.
536 <https://doi.org/http://dx.doi.org/10.1007/s10461-011-0112-y>

537 Sweeney, S. M., & Vanable, P. A. (2016). The Association of HIV-Related Stigma to
538 HIV Medication Adherence: A Systematic Review and Synthesis of the
539 Literature. *AIDS and Behavior*, *20*(1), 29–50. [https://doi.org/10.1007/s10461-](https://doi.org/10.1007/s10461-015-1164-1)
540 [015-1164-1](https://doi.org/10.1007/s10461-015-1164-1)

541 Thompson, M. A., Mugavero, M. J., Amico, K. R., Cargill, V. A., Chang, L. W., Gross,
542 R., ... Nachega, J. B. (2012). Guidelines for Improving Entry Into and
543 Retention in Care and Antiretroviral Adherence for Persons With HIV:
544 Evidence-Based Recommendations From an International Association of
545 Physicians in AIDS Care Panel. *Annals of Internal Medicine*, *156*(11), 817.
546 <https://doi.org/10.7326/0003-4819-156-11-201206050-00419>

547 Turan, J. M., & Nyblade, L. (2013). HIV-related stigma as a barrier to achievement of
548 global PMTCT and maternal health goals: a review of the evidence. *AIDS and*
549 *Behavior*, *17*(7), 2528–2539.

550 Van Vliet, K. J. (2008). Shame and resilience in adulthood: A grounded theory study.
551 *Journal of Counseling Psychology*, *55*(2), 233.

552 Visser, M., & Sipsma, H. (2013). The experience of HIV-related stigma in South
553 Africa. In *Stigma, Discrimination and Living with HIV/AIDS* (pp. 205–227).
554 Springer.

555 WHO. (2013). *WHO definition of Palliative Care*. WHO. Retrieved from
556 <http://www.who.int/cancer/palliative/definition/en/>

557 Wu, A. W. (1999). *MOS-HIV Health Survey. Users Manual*. Johns Hopkins
558 University. Retrieved from
559 [http://chipts.cch.ucla.edu/assessment/pdf/assessments/MOS-](http://chipts.cch.ucla.edu/assessment/pdf/assessments/MOS-HIV%20Users%20Manual%20%20Draft.pdf)
560 [HIV%20Users%20Manual%20%20Draft.pdf](http://chipts.cch.ucla.edu/assessment/pdf/assessments/MOS-HIV%20Users%20Manual%20%20Draft.pdf)

561

Table 1 Clinical and demographic characteristics of the sample (n=30)

Mean age (years, sd)	39.1 (6.9)
Gender (% female)	80%
Partner status , yes N (%)	17 (56.7%)
Number of children	
Mean (sd)	2.4 (1.4)
Median (IQR)	2 (2-3)
Number of financial dependents	
Mean (sd)	3.2 (2.0)
Median (IQR)	3 (2-4)
Education attainment N (%)	
None	3 (10.0%)
4 years or less	2 (6.7%)
Primary education	15 (50.0%)
Secondary education	10 (33.3)
Diploma	0 (0%)
CD4 count at baseline, Mean (sd)	348.13 (273.75)
Receiving TB treatment? Yes n (%)	5 (16.6%)
Received an AIDS diagnosis? Yes n (%)	30 (100%)
Owens a bicycle? Yes n (%)	8 (26.7%)
Owens a fridge? Yes n (%)	7 (23.3%)
Owens a television? Yes n (%)	18 (60%)
Owens a car? Yes n (%)	2 (6.7%)
Owens a radio? Yes n (%)	18 (60%)

Mental health summary score change on MOS-HIV MHSS	Control n(%)	Intervention n(%)
Improving (increase of 10 points)	6 (60%)	14 (70%)
Deteriorating (decrease of 10 points)	0 (0%)	1 (5%)
Static (no change of 10 points or more)	4 (40%)	5 (25%)

564

565

Table 2 Experience of HIV-associated stigma

Quote number	Quote
1	“Initially, I had a lot of [hesitates] ... friends, but when I knew about my status I started fearing them – because I feared they [hesitates] might be discussing about me”. <i>Woman, age 28, intervention arm ID 126</i>
2	“I was so afraid because in my entire life I never thought this disease would get me. I knew it was meant for some people with immoral behaviours within the community and I was living a straight upright life, even without a degree education.” <i>Woman, 33 years, control arm ID 158</i>
3	“[They said:] ‘You went and took your own illness. I told [you about] your husband - leave him, he will infect you with that illness, he likes a lot of women - now you see? Now you see?’” <i>Woman, 40 years, control arm ID 133</i>
4	“The way they used to talk about me, that I have this illness, and then they started isolating me. At first we were together but when they knew I had that illness they started isolating me, and that brought on the thoughts. When I look around, I can’t find any companion.” <i>Woman, 40 years, control arm ID 133</i>

567

568

569

570

571

Table 3 Effects of participation in the study

Quote number	Quote
5	<p>“Yeah, based on how we started, the way you showed me the importance, you enlightened me about this condition and the importance of my life. This made me to change and go back to my normal state and be like any other person.” <i>Woman, 39 years, intervention arm ID 106</i></p>
6	<p>“When you used to ask me questions, I used to feel much free inside ... I felt like a very normal person without any form of illness, I felt so good eh”. <i>Woman, 54 years, intervention arm ID 126</i></p>
7	<p>“I started viewing myself like any other person, as you see me now, like am not sick at all. I stopped worrying about myself and focused.” <i>Woman, 43 years, intervention arm ID 129</i></p>
8	<p>“...because thinking back when I used to be so ill, I saw it wise to kill myself with a rat poison [laughing], mixing it with a glass of water and drink it all [laughing] ... because there was no need staying on earth’s surface in so much pain and suffering, at times I felt like hanging myself... when I started coming here you [nurses] started advising me... since then I have been so close to God and never had a bad thought again. ... I dumped the rat poison in a pit latrine.” <i>Woman, 43 years, intervention arm ID 129</i></p>
9	<p>“I used to be soothed, such as being treated well, I mean I felt esteemed, that people here regarded me and treated me with respect”. <i>Woman, 39 years, intervention arm ID 106</i></p>
10	<p>“Now, I didn’t have anyone to talk to or someone to ask me, “How are you feeling, what do you think or how are you doing?” So when I came here I feel it really helped me because I found ... [hesitates] that day, I found people who were</p>

	very free and they talked to me very nicely. The way I was received – I really appreciate.” <i>Woman, 46 years, control arm ID 107</i>
11	“What I’d want to say is to appreciate you [the interviewer] for the service that I received here. I was treated so well till I started feeling like I’m really a human being. Indeed, this is place where you are treated with dignity to the point of appreciating yourself.” <i>Man, 44 years, intervention arm ID 123</i>
12	“So many things have contributed to these changes, but the greatest of all is me accepting myself in this condition and appreciating that this is my new way of life; another thing is the way you handle patients. For instance, one may come here broken hearted and feeling down but you would encourage and give him the best so many things contributed to this change.” <i>Woman 33 years, control arm ID 158</i>
13	“It has changed my thought, cleared my mind and my feelings also, I felt like one who matters in the society... I have changed and [the experience of participating in the study] made to accept myself as I am. It made my heart stronger and I proceeded on with my normal life.” <i>Woman 50 years, intervention arm ID 135</i>
14	“I had understood and accepted myself as I am; I was never ashamed any more but rather very open.” <i>Man, 43 years, control arm ID 97</i>
15	“I was only close to my brother amongst my family members and because I wasn’t open to him either, we never had a good relationship but during the study I changed. I could go to his house and explain my condition to him care free. So, our relationship has revived and we are free to each other.” <i>Woman, 33 years, control arm ID 158</i>
16	“The first advice I received when they diagnosed me to be positive they told me that, “mum you have the virus and you don’t need to panic in front of people because they will realize you have it, all you need to do is behave normally, don’t

	behave awkwardly and get rid of all the worries.” <i>Woman, 54 years, intervention arm ID 126</i>
17	“The most important thing was ... being able to express myself. To accept what has become of me and to say that this is what is happening but I can overcome it. This has been very nice and then a forum of expressing my innermost feelings and fears.” <i>Woman, 41 years, intervention arm ID 134</i>
18	“I just love the way I was being questioned in a polite tone that made me to open up my heart. I love the way you handle me in a friendly nice way.” <i>Woman, 33 years, control arm ID 159</i>
19	“You helped by asking me several questions on what was affecting [me], I felt like someone was helping me to carry my burden.” <i>Woman, 42 years, control, ID 130</i>
20	“It also helped me because when I started going there I used to be afraid but after coming here and got to be asked the questions, I started answering expressly, I found it to be of much help because I started feeling free.” <i>Woman, 46 years, control arm ID 107</i>
21	“[Participating] gave me the courage even to stand in front of anyone to share with them about myself.... I have a very good relationship [with those in my community] because I have disclosed my status to them. They have even nicknamed me – you know me as [name] they call me a minister. And do you know it’s a minister in charge of what? Minister for viruses! And I have accepted it.” <i>Woman, 36 years, control arm, ID 143</i>
22	I was scared when I first started this study, and my health was also not in a good condition when I started but as I came here for the discussions I started feeling ok, because I became free and started living my life as normal and when I told my

	family about my health, they also joined hands in supporting me.” <i>Woman 50 years, intervention arm ID 135</i>
23	“About my experience here, let me say that you people helped me a lot, because right now I can go out and tell or teach someone or approach someone, telling them to go and know their statuses. Never mind they’re the very, same people who were speaking ill about me. Yeah and I still reach out to them, counselling them and once they agree, I take them up to there [to the hospital to test for HIV]”. <i>Female, 36 years, control arm ID 143</i>

573

574

575

576

577

578

579