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### Title

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### Permalink

<https://escholarship.org/uc/item/7zw6824r>

### Journal

Journal of the International AIDS Society, 15(Suppl 2)

### ISSN

1758-2652

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### Publication Date

2012-07-01

### DOI

10.7448/ias.15.4.17391

Peer reviewed

## Short report

# Qualitative interviews with mentor mothers living with HIV: potential impacts of role and coping strategies

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### Abstract

**Introduction:** In South Africa where HIV prevalence is high, mentor mother programmes have been used to promote the health and wellbeing of women enrolled in government programmes preventing vertical transmission. The Masihambisane Project trained mentors to be educators and facilitators as “expert patients” in self-help groups. While this and other similar interventions demonstrate positive outcomes for mothers and their children, the long-term repercussions for mentors delivering the intervention are seldom considered. This article explores the personal impact of being a mentor, the potentially traumatizing effects of repeatedly sharing their experiences of living with HIV and the coping strategies they adopt.

**Results:** Towards the end of the Masihambisane intervention, 10 semi-structured qualitative interviews were conducted with locally recruited mentors living with HIV and were thematically analysed. Mentors found the repeated telling of their stories a painful reminder of adverse personal experiences. In some cases, retelling caused a physical reaction. Mentors relied on coping strategies like taking breaks, writing their experiences down and debriefing sessions. Despite the difficulties associated with their role, some mentors found being advisors and the group sessions therapeutic and empowering.

**Conclusions:** These findings indicate that the inclusion of peer mentors comes with certain responsibilities. While the mentors were resilient and some found the experience therapeutic and empowering found creative ways to cope with secondary trauma, the negative implications cannot be ignored. To effectively deliver a mentor-driven intervention to mothers enrolled in a programme to prevent vertical transmission, the possibilities of secondary trauma should be considered and mentors provided with ongoing counselling, training on coping skills and regular debriefing sessions.

**Keywords:** mentor mothers; expert patient; peer supporters; living with HIV.

**Received** 12 December 2011; **Revised** 12 March 2012; **Accepted** 7 May 2012; **Published** 11 July 2012

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### Introduction

South Africa has an estimated five million people living with HIV, with an antenatal HIV prevalence of 29.4% amongst pregnant women aged 15 to 49 years [1]. Several studies in South Africa have used local women living with HIV as mentors to support other women living with HIV enrolled in programmes preventing vertical transmission [2–4]. These studies report a range of positive psychological outcomes for the women enrolled, including a reduction in feeling alone and overwhelmed by their situation [4] and fewer reports of symptoms of depression [2,3]. The focus of these interventions and the reported outcomes are for the enrolled mothers. However, consideration must also be given to the potential repercussions for the mentors who deliver the interventions.

In the existing studies [2–4], mentors living with HIV are tasked with running self-help groups, facilitating education sessions and providing counselling to other women living with HIV. Mentors are trained and equipped with the knowledge to conduct self-help groups and, therefore, become what have been termed “expert patients” [5]. Mentors not only manage their condition but also draw on their training and lived

experience to support others and identify strategies for sharing experiences and encouraging healing [6,7].

Whilst the mentors are cast in a key helping role, they are also, by virtue of this role, at risk of experiencing secondary trauma. Secondary trauma is the emotional disruptions felt by those providing care or working closely with people who have been traumatized [8]. Helpers are indirectly affected as they experience similar emotional disruptions as those experienced by their traumatized clients. The extent to which a carer experiences secondary trauma tends to be compounded by their own history [5,9]. This paper explores the personal impact of being a mentor and the potentially traumatizing effects of repeatedly sharing their experiences of living with HIV as a way of demonstrating challenges of and managing living with HIV. The paper also looks at the coping strategies adopted by mentors to mitigate these effects.

### Methods

Project Masihambisane was a mentor-mother vertical transmission intervention implemented in rural KwaZulu-Natal South Africa, between 2008 and 2010. The aim of the

intervention was to improve the health and wellbeing of pregnant women and their babies. Women living with HIV and enrolled in the South African Department of Health's (DoH) programme to prevent vertical transmission were provided with peer support and education by mentors, trained women living with HIV [3,10]. Matched clinics offering these services were selected, and four clinics were randomly assigned as intervention clinics and four as control clinics. At the intervention clinics, women were invited to attend four antenatal and four postnatal small group sessions facilitated by mentors. Women in the control clinics received standard-of-care DoH services for the prevention of vertical transmission [10]. Group sessions covered issues such as disclosure, HIV prevention, treatment adherence, family health, vertical transmission and coping with symptoms of anxiety and depression [3].

The 10 black African *isiZulu*-speaking mentors who were interviewed for this study were recruited at the intervention clinics. All had previously tested positive for HIV. The mentors were all from the local community and were aged between 22 and 35 years. All except two were single and eight of the women had had at least one child and, therefore, had been previously enrolled in the government's vertical transmission programme. Mentors were selected using the theory of positive peer deviants [10]. That is, the mentors were chosen because they were living positively with HIV and both they and their children were flourishing. The women chosen were positive role models with a history of community engagement who were willing to use their experience to help others.

Mentors underwent extensive formal training provided by the research team on issues such as disclosure, counselling, communication skills and group facilitation [3,10]. In addition, the mentors were educated about and equipped with the skills to run group sessions. The mentors were paid a stipend equivalent to the DoH's community health workers for their activities in the intervention clinics. Mentors were responsible for leading the group sessions and conducting individual counselling sessions with participants. To support mentors in their role, monthly debriefing sessions were provided by a counselling psychologist.

Towards the end of the intervention, semi-structured qualitative interviews were conducted with the mentors in order to understand their experience of their role. The interviews dealt with the effects of repeatedly sharing their HIV disclosure and testing experiences and the coping strategies they drew on. Interviews were conducted in the mentors' first language *isiZulu*, audio-taped, transcribed and translated into English for analysis and interpretation. The transcribed interviews were coded by the first and second authors, using themes defined by the research questions and emerging from multiple coding iterations of the transcripts. This analysis yielded observations of several patterns both within and across the women's experiences [9]. Informed consent was obtained for all interviews. Ethical approval was received from the Institutional Review Board of the University of California, Los Angeles, and the Research Ethics Committee of the Human Sciences Research Council, South Africa.

## Results

### Current stories trigger painful memories

Mentors were trained to disclose their HIV status at each session and encouraged to share their own experiences of living with HIV. Most mentors found the repeated disclosures and providing accounts of their stories painful. Equally difficult was hearing their clients' stories, as these often triggered painful memories of their own sometimes traumatic histories. For example, the sessions reminded one mentor of losing her baby to AIDS:

*Tell[ing] them from session one to session eight that I lost my child, it hurt me, as thoughts of my baby came back (35-year-old woman).*

In sharing her experience, another mentor spoke of being reminded of her partner's desertion after disclosing her status to him. Others spoke about struggling to come to terms with living with HIV and how clients' situations reminded them of these challenges and their unresolved personal predicaments:

*You see another person HIV-positive, having yourself gone through that situation you feel a lot of pain (30-year-old woman).*

### Physical and emotional reaction

In addition to clients' stories triggering mentors' memories, some mentors found hearing clients' stories traumatic and distressing. This resulted in strong physical reactions in some mentors. One mentor described having nightmares about disclosing her status to her family. Others described experiencing shortness of breath, becoming intensely emotional and crying during sessions:

*I would feel sad and cry again, because she is telling me about her problems (29-year-old woman).*

These reactions were not always easy to control. A number of mentors spoke about needing to suppress their reactions in sessions to prevent negative consequences for the group:

*You must not show that you are shocked, so I try to calm down, but when [they have] gone ... oh my God (29-year-old woman).*

One mentor mentioned how she sometimes felt like sleeping after the sessions because she was so emotionally and physically drained.

### Healing and empowerment

Despite the fact that all mentors found the repeated disclosures of their HIV status and personal histories painful, a few viewed their role in positive terms. They felt that it contributed to personal healing. Mentors mentioned that they felt good about helping others in a similar predicament and that the structure of the group provided an opportunity for helping others as well as for self-development:

*It builds me up to be able to tell someone else about my situation, and be able to advise them that they can also be successful if they do this and that (30-year-old woman).*

For these mentors, the group sessions were therapeutic:

*I know that I shouldn't concentrate on my story [during sessions with mothers] but just being able to talk about my status ... it helps me a lot. (30-year-old woman).*

The training they received coupled with their participation in group sessions enabled them to deal better with their own situations. One mentor recounted how working on the project empowered her to deal with her own disclosure:

*... when I joined Masihambisane being in the support group helped me a lot because I even became able to tell my family (32-year-old woman).*

Some mentors also spoke about the value that employment brought to them and their families and that employment as a mentor gave them a sense of empowerment.

### Coping strategies

Mentors intuitively developed various strategies to manage the effects of their role both during and after sessions. The coping mechanisms mentors adopted within the sessions included drinking water to calm down or going outside to get some air when they felt overwhelmed:

*I will feel that tears are filling my eyes, but I'll have to hold them back so that the client does not see the ... my body gets all tense and I have a headache ... sometimes I cry. Sometimes I get out and just want to be by myself, it does help me, going outside sometimes if there is water I'll drink some. Then [the emotions] will slowly disappear (33-year-old woman).*

This was a way for mentors to fulfil their responsibilities and also limit the disruption caused to their clients by their own overwhelming emotions. The mentors were conscious of making sure that their reaction did not make their clients feel uncomfortable and therefore felt it was important to conceal their emotions or not let the things being said in the sessions affect them. When asked how she coped, one mentor responded:

*It is just by being courageous, being the one, who comforts her by telling her that if things are this way this is what you do. And to not allow a situation where she is the one who sees tears from me, because she is going to realize that this problem she has is worse than mine (22-year-old woman).*

Even in the group sessions, which were primarily a forum for clients, mentors found support. The sessions helped the mentors cope with their realities of living with HIV:

*On a particular day when we are sitting as a group I do talk, cry ... because I, myself, do need their support ... because they also need mine (30-year-old woman).*

Some mentors also adopted strategies they found useful to cope at the end of a session, such as creating the space and time alone to think about and process the day's events

or to pray. Others found talking to other people a helpful coping strategy:

*What causes [my stress] to gradually go down is the fact that I talk about it. Maybe a person asks me, "What did you do when this was happening?" Then telling them my story helps me a lot (35-year-old woman).*

Another mentor spoke about writing her thoughts and emotions in her diary:

*Sometimes things flood back into my mind and I end up writing down in my diary on my arrival at home (29-year-old woman).*

### Discussion

The findings from this qualitative study point to some of the potential consequences of including mentors to lead self-help groups and as "expert patients" in peer support interventions. Although the process was designed for the mentor to support the client, we found that, similar to findings of a programme in the UK, the sessions became a reciprocal therapeutic space for some mentors [11]. In this study, mentors were well trained and had first-hand experience of living with HIV and had therefore become "experts" [5]. The knowledge and responsibility they were able to achieve through their employment helped to make the mentors feel empowered [5]. They also used the self-help group as a place for healing and for self-development as well as a way of helping others to do the same [6,7]. Despite the possible positive repercussions, many of the mentors found their role challenging and developed physical and emotional symptoms that are suggestive of posttraumatic stress or secondary trauma. These reactions may have been compounded by the realities of living with HIV in a context where issues of stigma, discrimination and lack of acceptance of HIV are still a reality [12]. Mentors were conscious of the effect that their emotional reactions may have for their clients and adopted ways to suppress or cope with these to protect the members of their groups. Mentors were innovative and resilient in the coping strategies they adopted to manage the effects of assisting others similar to themselves.

Our study highlights the potential complexity of these mentors' role and the possible consequences of secondary trauma for their emotional and physical wellbeing [8,13]. These findings also suggest the need for further larger-scale research into the impact of being a mentor.

This study has a number of limitations. No pre-intervention assessment of the women was conducted, and despite all mentors having known their HIV status for some time, this duration was not recorded. Further studies would benefit from collecting this information to assess whether it affects mentors' experiences. The study also includes only a small sample. Despite limited generalizability, we argue that the findings could have important implications for mentors working in similar contexts. This study is exploratory and the detailed nature of the analysis begins to provide us with a depth of understanding of the mentor's experiences not yet offered elsewhere. The results of this study suggest that there is definitely scope for further consideration of the role

of mentors in the delivery of a peer-based intervention such as Masihambisane.

## Conclusions

These findings show that including peer supporters or mentors comes with certain responsibilities. While the mentors were resilient and some found the experience therapeutic and empowering and found creative ways to cope with secondary trauma, the negative effects of their role cannot be ignored. To effectively deliver a mentor-driven intervention for mothers enrolled in a programme to prevent vertical transmission, the possibilities of secondary trauma should be considered. Mentors must be provided with ongoing counselling, training in coping skills and regular debriefing sessions. Further research could consider mentors long-term experiences both prior to and after involvement in an intervention. In addition, further research could consider the feasibility of women living with HIV taking on a similar role on a long-term basis and issues such as retention and attrition.

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### Competing interests

The authors declare that they have no competing interests.

### Authors' contributions

Lebohang Dhlamini took the lead on the conceptualization of the paper and analysis of the data. She drafted an initial version of the paper. Lucia Knight and Heidi van Rooyen helped in the conceptualization of the paper, interpretation of the data and edited several drafts of the paper. Alastair van Heerden and Mary Jane Rotheram-Borus reviewed and commented on the final version of the paper. All authors have read and approved the final version.

### Acknowledgements

The authors would like to thank Lungile Mkhize for conducting the interviews and for her role during the intervention of mentoring and supervising the mentors. We are grateful to all the mentors employed during the study and

especially those who were interviewed for this paper. Lastly, we thank Andile Sibiyi for transcribing and translating all the interviews.

## References

1. National Department of Health. National antenatal sentinel HIV and syphilis prevalence survey in South Africa 2010, Pretoria, National Department of Health; 2011.
2. Futterman D, Shea J, Besser M, Stafford S, Desmond K, Comulada WS, et al. Mamekhaya: a pilot study combining a cognitive-behavioral intervention and mentor mothers with PMTCT services in South Africa. *AIDS Care*. 2010;22:1093–100.
3. Richter L, Rotheram M, van Heerden A, Rochat T, Stein A, Tomlinson M, et al. PMTCT outcomes for mothers living with HIV and their infants in South Africa: A randomised clinic trial of HIV+ peer mentors. *PLoS Medicine*. Submitted May 2012.
4. Teasdale CA, Besser MJ. Enhancing PMTCT programmes through psychosocial support and empowerment of women: the mothers2mothers model of care. *South Afr J HIV Med*. 2008;9:60–4.
5. Tattersall RL. The expert patient: a new approach to chronic disease management for the twenty-first century. *Clin Med*. 2002;2:227–9.
6. Cassidy R. Global expectations and local practices: HIV support groups in the Gambia. *AIDS Care*. 2010;22(Suppl 2):1598–605.
7. Walch SE, Roetzer LM, Minnett TA. Support group participation among persons with HIV: demographic characteristics and perceived barriers. *AIDS Care*. 2006;18:284–9.
8. Bell H. Strengths and secondary trauma in family violence. *Soc Work*. 2003;48:513–22.
9. American Psychiatric Association. *Diagnostic & statistical manual of mental disorders IV-TR* (4th ed-TR), Washington DC. 2000;429–84.
10. Rotheram-Borus MJ, Richter L, Van Rooyen H, van Heerden A, Tomlinson M, Stein A, et al. Project Masihambisane: a cluster randomised controlled trial with peer mentors to improve outcomes for pregnant mothers living with HIV. *Trials*. 2011;12:2.
11. Knudsen-Strong E. *From pregnancy to baby and beyond: preliminary findings from an evaluation of the pilot programme*, London. The London School of Economics and Political Science, MSc Health, Community and Development; 2011.
12. Genberg BL, Hlavka Z, Konda KA, Maman S, Chariyalertsak S, Chingono A, et al. A comparison of HIV/AIDS-related stigma in four countries: negative attitudes and perceived acts of discrimination towards people living with HIV/AIDS. *Soc Sci Med*. 2009;68:2279–87.
13. Lerias D, Byrne MK. Vicarious traumatization: symptoms and predictors. *Stress Health*. 2003;19:129–38.