

Living with HIV, disclosure patterns and partnerships a decade after the introduction of HIV programmes in rural South Africa

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Prevention of mother-to-child Transmission and HIV Treatment programmes were scaled-up in resource-constrained settings over a decade ago, but there is still much to be understood about women's experiences of living with HIV and their HIV disclosure patterns. This qualitative study explored women's experiences of living with HIV, 6–10 years after being diagnosed during pregnancy. The area has high HIV prevalence, and an established HIV treatment programme. Participants were enrolled in a larger intervention, "Amagugu", that supported women ($n = 281$) to disclose their HIV status to their children. Post-intervention we conducted individual in-depth interviews with 20 randomly selected women, stratified by clinic catchment area, from the total sample. Interviews were entered into ATLAS.ti computer software for coding. Most women were living with their current sexual partner and half were still in a relationship with the child's biological father. Household exposure to HIV was high with the majority of women knowing at least one other HIV-infected adult in their household. Eighteen women had disclosed their HIV status to another person; nine had disclosed to their current partner first. Two main themes were identified in the analyses: living with HIV and the normalisation of HIV treatment at a family level; and the complexity of love relationships, in particular in long-term partnerships. A decade on, most women were living positively with HIV, accessing care, and reported experiencing little stigma. However, as HIV became normalised new challenges arose including concerns about access to quality care, and the need for family-centred care. Women's sexual choices and relationships were intertwined with feelings of love, loyalty and trust and the important supportive role played by partners and families was acknowledged, however, some aspects of living with HIV presented challenges including continuing to practise safe sex several years after HIV diagnosis.

Keywords: maternal HIV disclosure; partnerships; HIV treatment; stigma; family

Introduction

Successful prevention of mother-to-child-transmission (PMTCT) and HIV treatment programmes have reduced mortality and resulted in HIV-positive women living longer to care for their children who are mostly HIV-uninfected (WHO, 2013). Keeping women alive is beneficial for children, and associated with decreased child mortality in highly prevalent HIV settings (Ndirangu, Newell, Tanser, Herbst, & Bland, 2010; Ndirangu, Newell, Thorne, & Bland, 2012).

Much is known about the clinical health of HIV-infected women in resource-constrained settings (Coutsoudis et al., 2010; Miiró et al., 2009), however, less is known about their experiences of living with HIV several years after their diagnosis, and to whom they have disclosed. Emerging literature on HIV disclosure describes both positive and negative outcomes following disclosure; increased social support has been reported (Bouillon et al., 2007; Groves, Maman, & Moodley, 2012; Maman et al., 2003) violence and abandonment have also been documented (Linda, 2013; Medley, Garcia-Moreno, McGill, &

Maman, 2004). There is a dearth of evidence from longitudinal research in African settings to inform adherence support programmes (Bärnighausen, Tanser, Dabis, & Newell, 2012; Dewing et al., 2012; Santer, Ring, Yardley, Geraghty, & Wyke, 2014) and limited data on client perspectives of antiretroviral treatment (ART) services (Orner et al., 2008).

This qualitative study explores the experiences of 20 HIV-infected women, who learnt their HIV diagnosis during pregnancy as participants in the Vertical Transmission Study (VTS; 2001–2006), rural South Africa (Bland, Coovadia, Coutsooudis, Rollins, & Newell, 2010; Coovadia et al., 2007; Mkwazazi et al., 2008). It explores their experiences of living with HIV and taking ART, their partnerships and issues of access and equity to treatment.

Methods

The setting

This study was conducted in northern KwaZulu-Natal, at the Africa Centre for Health and Population Studies

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(www.africacentre.com). The setting is rural, resource-limited and predominantly Zulu speaking (Bärnighausen, Tanser, Malaza, Herbst, & Newell, 2012; Tanser et al., 2008).

In 2001 the Department of Health, in partnership with the Africa Centre, launched a PMTCT programme and, in keeping with policy at the time, single-dose Nevirapine was offered to HIV-infected women during labour, and their infants post-partum. Since then PMTCT regimens have changed, and now all HIV-infected pregnant women, not already on treatment, receive ART at their first antenatal visit (WHO, 2013). Since 2004 an HIV Programme has provided free HIV treatment and care in a devolved programme at primary health care clinics in the area (Bland & Ndirangu, 2013; Houlihan et al., 2010; Janssen, Ndirangu, Newell, & Bland, 2010). Initially, the eligibility criteria for ART was a CD4 cell count of ≤ 200 cells/ml, but since 2014 has been extended to include all those with a CD4 cell count of ≤ 500 cells/ml (WHO, 2013).

Measures

This qualitative study was undertaken with a sub-sample of women who had participated in two intervention studies, one to support exclusive breastfeeding to reduce vertical transmission of HIV (“VTS”; Bland et al., 2010) and the other to support maternal HIV disclosure (“Amagugu”; Rochat, Arteché, Stein, Mkwanazi, & Bland, 2014). The aim of this qualitative research was to better understand women’s experiences of living with HIV over a long period of time, and to explore their experiences of participating in the VTS and Amagugu interventions. A two-part interview guide was developed: Part One was open-ended and explored women’s experiences of being HIV-infected since their diagnosis in the VTS and is the subject of this manuscript. Part Two focused on their experiences of participating in the Amagugu intervention, the subject of a separate analysis. The interview started with an open-ended narrative and then included topic area probes. The open-ended question was: “Tell me about your life since we last saw you in the VTS”. Through these interviews we sought to address less understood psychosocial topics about women of child-bearing age, highlighted in the literature, including HIV testing during pregnancy, safe sex negotiations and experiences of living with HIV (McGrath, Richter, & Newell, 2013; Rochat et al., 2006; Varga, Sherman, & Jones, 2006). The probes explored the following:

- (1) Women’s experiences of access to HIV care and treatment.
- (2) Women’s experiences of their sexual partnerships since the VTS.

Sample

HIV-infected women included in these analyses were a sub-sample of participants enrolled in the Amagugu study, who had received support to disclose their HIV status to their 6- to 10-year-old child (Rochat, Mkwanazi, & Bland, 2013; Rochat et al., 2014). Women had first been tested for HIV in the local PMTCT programme and had known their HIV status for at least six years (Mkwanazi et al., 2008). The Amagugu disclosure intervention targeted the VTS index child specifically, but mothers were encouraged to disclose their status to their other children post-intervention. Resources and time available determined the initial sample size and we purposefully selected 20 participants from five of the nine clinic areas in which the Amagugu study operated, representing urban and rural settings. After completion of the 20 interviews a preliminary round of data analysis was undertaken and it was concluded that saturation had been reached.

Data collection

Socio-demographic and disclosure data were collected during a baseline survey in the Amagugu intervention. Two months after completing the intervention one of the researchers (NM) contacted the sample of women by telephone, explained the qualitative study and requested an appointment to conduct individual in-depth interview; all 20 women agreed to participate and provided written, informed, consent.

Data preparation and analysis

The in-depth interviews lasted approximately 60 minutes at the women’s homes were tape recorded, transcribed verbatim and translated from isiZulu to English by NM. All interviews were read several times for familiarity with the data and the transcripts were entered into ATLAS.ti computer software for coding of common themes (Friese, 2012). NM analysed the interviews by category to determine common elements, patterns and themes within each participant’s interview. These were coded and compared across interviews to determine dominant thematic areas within the content areas. To ensure researcher reflexivity, NM, who is herself a Zulu woman, kept detailed daily notes of personal reactions to, and reflections on, interview content, which might inform interpretation bias. Transcripts were then independently reviewed by the second author (TJ) after which all three authors reviewed the results to reach consensus on the most salient themes, their organisation and to explore aspects of researcher reflexivity.

Results

The characteristics of participating women are shown in Table 1. Their median age was 32 years (IQR 29–37); their children's median age was seven years (IQR 6.5–7.5). Of the five women reported as married, two were legally married and three were engaged; of those reported as unmarried ($n = 14$), 12 had current partners and approximately half were living with their current partner. HIV exposure in the households was high with most women ($n = 14$) reporting that another adult family member was HIV-infected. The majority of women were on ART ($n = 14$), with a median CD4 cell count of 430 (IQR 310–554) cells/ml; one woman eligible for treatment had not accessed ART.

Table 2 presents people to whom the women had disclosed their HIV status. More than half had disclosed to their current partners ($n = 13$), half of whom were also HIV-infected. Two women had not disclosed to anyone due to fear of HIV-related stigma.

In total, the 20 women had 56 biological children, aged 2–18 years, of whom 43 were reported to have been tested for HIV and were HIV negative. One mother reported that she had disclosed her HIV status to her 12-year-old, HIV negative, child, a sibling of the study child, prior to the intervention. Post-intervention, all mothers had disclosed to their study children – 10 fully (i.e., explained they had HIV) and 10 partially (i.e.,

explained they had a “virus” of whom six mothers subsequently fully disclosed).

In data analysis two main themes emerged:

- (1) Living with HIV and normalising ART.
- (2) Love, partnerships and sex.

Theme 1: Living with HIV and normalizing ART

At the time of diagnosis, HIV testing had recently been introduced into the study area, and HIV prevalence amongst pregnant women was high (approximately 40%). This led to suspicion or disbelief about a positive HIV test, for the women and some of their families:

You know when you are at the clinic and you are checking and you ask one another: “How come we all are found to be infected?” They must be playing with us. You don't pay attention to anything. When you suffer from things such as headaches then you start paying attention. (29-year-old)

However, given the increased access to ART in the years following the VTS, the majority of women shared experiences of living positively with HIV. Availability of ART was considered a privilege previously denied to many, and this changed how women perceived HIV:

At home we were eight, now only four are left. My sister left a 9 month old child who is now 16 years old. So,

Table 1. Characteristics of the 20 women that were interviewed.

Study Number	Maternal age (years)	Child age (years)	Child sex	Marital status	PMTCT Site	Currently employed	Bore child after index child	Last CD4 cell count result cells/ml	Currently on ART
1	26	7	F	Single	Peri-urban	No	Yes	105	Yes
2	32	6	M	Single	Peri-urban	No	Yes	568	Yes
3	32	7	F	Single	Rural	Yes	Yes	379	No ^a
4	44	8	M	Single	Peri-urban	Yes	No	800	Yes
5	46	7	M	Married	Peri-urban	No	No	700	Yes
6	36	6	F	Married	Peri-urban	Yes	No	297	Yes
7	37	7	M	Single	Rural	No	No	487	Yes
8	49	8	F	Widowed	Rural	No	No	219	Yes
9	28	6	F	Single	Rural	No	No	212	Yes
10	39	8	F	Married	Rural	Yes	No	467	Yes
11	28	7	F	Single	Rural	No	Yes	629	No
12	32	7	M	Married	Rural	No	Yes	518	Yes
13	37	7	M	Single	Rural	No	Yes	400	Yes
14	38	6	F	Married	Rural	Yes	Yes	350	Yes
15	31	8	F	Single	Rural	No	Yes	709	No
16	36	7	F	Single	Rural	Yes	Yes	459	No
17	28	6	F	Single	Rural	No	Yes	300	Yes
18	29	8	M	Single	Rural	Yes	Yes	320	No*
19	32	7	F	Single	Rural	No	No	540	No
20	29	7	F	Single	Rural	No	Yes	394	Yes

^aAt the time of the interview ART eligibility criteria was ≤ 350 cells/ml.

Table 2. HIV disclosure of participating women.

Study number	In a relationship with the child's father	Lives with current partner	Partner HIV positive	Aware of other adult family members with HIV	Disclosed to current partner	Disclosed to parent	Disclosed to sibling	Disclosed to friend	Disclosed to other relative	Disclosed to religious person	Whom disclosed to first
1	No	No	No	Yes	No	No	No	No	Yes	No	Partner
2	No	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Parent
3	No	Yes	Yes	Yes	No	No	No	No	No	No	No disclosure
4	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	No	Partner
5	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	Parent
6	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No	Partner
7	No	Yes	No	Yes	Yes	No	Yes	Yes	Yes	No	Sibling
8	Yes	No	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Partner
9	No	No	Yes	Yes	Yes	No	Yes	Yes	No	No	Sibling
10	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Friend
11	No	No	No	No	Yes	No	Yes	Yes	No	No	Friend
12	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	No	Partner
13	Yes	No	No	Yes	No	No	No	No	No	No	No disclosure
14	Yes	No	No	No	Yes	No	No	Yes	No	No	Partner
15	Yes	No	No	No	No	No	No	No	No	No	Partner
16	Yes	Yes	Yes	Yes	Yes	No	No	No	No	No	Partner
17	No	No	No	Yes	No	Yes	No	No	No	No	Parent
18	No	No	No	Yes	No	No	No	Yes	Yes	Yes	Other relative
19	No	No	No	No	No	No	No	No	Yes	No	Other relative
20	No	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Partner
Total	10	9	8	14	13	5	9	11	11	4	

when we take pills [ART] now, we are taking them for the reason that we had siblings who died without getting help. Children were left without parents. I have survived, and now free pills are available. (46-year-old)

Most women were taking ART, regularly attending ART clinics and knew other HIV-infected people, which helped to reduce stigma:

Sometimes you see others hiding by the corners when they attend HIV clinics, I do no such [thing]! People are taking their own pills for BP [blood pressure problems], arthritis, why? They want to live. I'm taking ARVs [antiretroviral drugs] because I want to live. If we all die, the tomb does not say this one was killed by AIDS, this one was killed by BP. We are all dead! When I go to the clinic I even strut my stuff. I don't care that ARVs have made me have thin legs and flat buttocks, eish! [Laughter]. (46-year-old)

There was a sense of HIV causing a chronic, rather than fatal, illness and pride rather than shame in going to HIV clinics:

Most of my neighbours are open now; we even lend each other pills. They come and say we have come to borrow our "teabag". I was counting that I have been taking ARVs for 10 years. We are going to push my husband in a wheel barrow [when he gets sick] because he does not want to test. (46-year-old)

As women settled into longer term HIV care they became increasingly concerned about the quality of health services and understanding more about their illness. Women described becoming selective about ART clinics based either on the quality of care received, or on being able to attend the same clinic as a partner:

I also want to change from Clinic A to Clinic B, they are not safe there. They sometimes give you pills that are not enough. They are careless. I go to Clinic B because my partner also took his ARVs there and sometimes we can walk to town together. (26-year old)

Some women expressed confusion over the clinical course of HIV infection, and were perplexed about the relationship between CD4 counts and their physical health:

I just started ARVs six months ago. When I checked I discovered that my CD4 count was 112. I was beyond shocked, I can't explain it. I was dead walking. I felt fine. I realised that is why people just drop dead. (37-year-old)

Theme 2: Love, partnerships and sex

All women agreed that partnerships were complex and discordant HIV results presented particular difficulties:

He showed me his negative results. I thought how can I show him my positive result? I told my sister my fear was if I say I'm positive he will say I am the one who brought the virus. We discussed with my sister that we have to plan how we are going to tell him because he has to be protected and we should not practise unsafe sex. (37-year-old)

When I disclosed, he did not want to accept it. He did not fight me though; I think it is because he knows of his ways. We continued getting other children. I also do not want to lie; when I discovered my HIV status, it was not such an issue. (29-year-old)

Women reported that some partners were accepting of their HIV status, and supportive, despite discordant results:

I am a kind of a person that discloses everything. I always have my ARVs with me, openly. I'm visiting here but I have them openly with my cosmetics. When I disclosed to my partner he said: "I wonder how you got it". I said maybe I have had too many children, maybe I was helping someone. He did not fight with me. He said he was also going to go to the clinic to test and he did. He goes every six months and is negative. Maybe he has strong soldiers [CD4 cells] because they cannot detect it [HIV]. I tell him he will end up starting treatment or he will just fall and die but we are using condoms. (32-year-old)

Some partners provided finances for women's children, although they were not the biological fathers. While this made the partner more attractive, it also complicated disclosure due to women's fears of abandonment:

... on Thursday he said let's go and see "o-small" [the small ones, my children not his] and we first went to the shop. I thought we were just buying snacks but he said: "Don't they eat? Take rice". And we packed the trolley and took the stuff to them. So, when you have such people you don't want to spoil things and you think this is my last chance if I do not use it I will not find someone like him. (32-year-old)

Despite knowing about safe sex, women articulated that they were not consistent with condom use, talking about their own weaknesses, rather than male coercion which is often reported in the literature:

Sometimes there are things that make you weak and your resistance crumbles. Sometimes it happens that someone judges you and they think this one is fine she has nothing. That mistake happens sometimes, I don't want to lie but it's not an everyday mistake, I try to avoid it. I try to be strict. (29-year-old)

Discussion

This qualitative study adds to the literature about the lives of rural, African, women living with HIV, including

their disclosure patterns (Stevens & Galvao, 2007; Varga et al., 2006). We found high levels of stability in partnerships with half the women still in a relationship with the biological father of the child, only two of whom had not disclosed to them. Approximately half the women had disclosed to their partners first and their broader family network subsequently, suggesting that stability of partnerships (reflected by duration and co-residency) is an important facilitator of partner disclosure, as documented in the literature (Alemayehu, Aregay, Kalayu, & Yebyo, 2014; Antelman et al., 2001; Bachanas et al., 2013; Mayfield Arnold, Rice, Flannery, & Rotheram-Borus, 2008; Medley et al., 2004). Our finding that partners were generally described as being supportive is similar to findings from other parts of Africa and Asia (Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, 2008; Medley et al., 2004; Skunodan et al., 2006). Importantly, for many women HIV disclosure did not necessarily facilitate low risk behaviours, raising questions about the support couples might need beyond the disclosure itself. The 2012 WHO Couple Counselling Guidelines highlights that couple counselling has not received programmatic attention especially in situations of HIV sero-discordance (WHO, 2012), and studies have shown that couple counselling support has an important role in facilitating long-term ART adherence (Anglemyer, Horvath, & Rutherford, 2013; Brown et al., 2011).

High HIV prevalence rates in the study area, and the political climate during women's diagnosis at pregnancy, led to suspicion about the existence of HIV, but women reported gradual acceptance of HIV as a chronic illness. In the early years of the epidemic there was significant focus on stigma and its impact on testing, however, this research suggests that, with increased access to treatment, stigma is reduced (Maman et al., 2009), and most women were living positively with HIV and taking ART without fear. However, as they stabilised on ART their needs changed and they expressed new concerns including quality of health care and counselling support. With large numbers of people attending HIV clinics, counsellors are often trained to give generic information to everyone to maximise efficiency, and seldom have time to address individual concerns or for health promotion. Counselling training curricula need to evolve to include issues such as discordant results in relationships (Dworkin & Ehrhardt, 2007), the challenges of living with a chronic disease and ART adherence (Rochat, Bland, Coovadia, Stein, & Newell, 2011). Offering family-centred, rather than individual, care may hold particular advantages for women and their families in high prevalence settings (Betancourt, Abrams, McBain, & Fawzi, 2010; Kairania et al., 2010; Richter, 2010).

To date literature on gender and HIV has often portrayed men as determinants of women's HIV risk (Dunkle et al., 2004; Greig, Peacock, Jewkes, & Msimang, 2008), and while this is mostly correct, the contribution of this research is important as it presents a more assertive, women's voice, with women gaining autonomy over their health through access to care, and the ability to make decisions about their sexual health. The vast majority of research supporting a particularly gendered perspective on risk is cross-sectional rather than longitudinal, and may, by its design, preclude a clear understanding of how women's power and independence in relationships may change over time in stable partnerships. This research highlights that sexual health resides within love relationships which are complex, and it is this complexity that informs the decisions women make in relation to HIV care.

Conclusion

The wide-scale roll-out of HIV prevention and treatment programmes have brought about considerable changes for women who are now surviving to parent children in a society that has less HIV-related stigma. However, the transition to longer term care raises new challenges, including securing quality family-centred care and dealing with disclosure in new sexual partnerships. The narratives of this group of women contribute to understanding the challenges of African HIV-positive women of childbearing age in the ART era.

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