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Original Article

The Amagugu intervention: a qualitative investigation into maternal experiences and perspectives of a maternal HIV disclosure support intervention in rural South Africa

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Abstract

The World Health Organization recommends disclosure of parental HIV to children aged 6–12 years. The maternal HIV-disclosure intervention (Amagugu), a lay counsellor-led, home-based intervention with six sessions, was implemented. The intervention included provision of disclosure tools, training and support for mothers, a family session and health promotion clinic visit for mothers and children. Amagugu demonstrated success as a maternal disclosure support programme but less is known about the experiences of participants. A sub-sample of HIV-infected mothers ($n = 20$) with primary school-aged HIV-uninfected children, from Amagugu, was purposely selected. Using semi-structured interviews and interview-guide, we explored maternal perceptions of disclosure prior to participation and experiences of participating in Amagugu. Audio-recorded interviews conducted in participants' homes, in isiZulu, were transcribed, and content analysis was undertaken. The most common reasons for prior non-disclosure were concerns about children's developmental capacity to understand HIV, fear of HIV-related stigma towards mothers and their families, and lack of skills to undertake disclosure. Intervention materials, rapport with counsellors, and flexibility of the proposed disclosure process motivated mothers to participate. While expressing satisfaction with the intervention, some mothers remained concerned about their children's understanding of HIV and ability to maintain confidentiality. Mothers also requested support in discussing sex-related topics with their children. Despite prior high rates of disclosure to other adults, mothers had little awareness about the importance of disclosure to children and lacked skills to undertake this. The intervention approach, rapport with counsellors, and practicality of the materials, helped overcome child disclosure barriers. Mothers reported their children as very supportive following disclosure and stated they would advise other women to disclose to children for practical support around HIV treatment adherence. This qualitative evaluation suggests that mothers with primary school-aged children may require structured support when disclosing to children, which could be achieved through supportive home-based counselling and user-friendly materials.

Keywords: Maternal HIV, disclosure, Africa, family-based intervention, HIV-exposed children, qualitative research, research participation

Key Messages

- Participant engagement and involvement in intervention development and evaluation can improve outcomes.
- Specific interventions are needed to support and encourage parental HIV disclosure to children.
- Child's developmental capacity and inability to handle HIV information is the most common barrier to disclosure.
- Flexibility and the intervention package are motivators for participation.

Introduction

Advances in HIV treatment and prevention have resulted in fewer HIV-infected children born to HIV-infected mothers (Burton *et al.* 2015). HIV-exposed but uninfected children are a growing population with estimates suggesting that between 30% and 50% of HIV-uninfected children in Sub-Saharan Africa currently live with HIV-infected parents, most frequently their mothers (Short and Goldberg 2015). A growing body of literature on the impact of parental HIV on children has illustrated that these children are at risk of poor health and educational outcomes (Chi and Li 2013; Cluver *et al.* 2013, Goldberg 2014; Jao *et al.* 2016) and that their parents need support with the complexities of parenting with HIV (Rochat *et al.* 2011; Mkwanazi *et al.* 2012; Lachman *et al.* 2014; Sherr *et al.* 2014). An important issue facing all HIV-infected parents is how and when to disclose their HIV status to their children and families.

In 2011, based on growing evidence on the benefits of disclosure to children (Krauss, Letteney et al. 2013), the World Health Organization (WHO) recommended that parents disclose their own HIV status to their children, between 6 and 12 years of age (World Health Organization 2011). Benefits of disclosure include improved family cohesion and mother–child relationships (Pilowsky *et al.* 2000; Schrimshaw and Siegel 2002; Vallerand, Hough *et al.* 2005; Murphy *et al.* 2009), improved maternal mental health (Armistead *et al.* 1997; Wiener *et al.* 1998; Armistead *et al.* 2001; Schrimshaw and Siegel 2002; Brackis-Cott *et al.* 2007), increased social support and improved maternal physical health due to improved ART adherence (Tompkins *et al.* 1999; Murphy *et al.* 2001; Letteney 2006). However, despite these reported benefits, disclosure rates are low (Qiao *et al.* 2011; Mkwanazi *et al.* 2012; Krauss *et al.* 2013) and very little research on parental support to undertake disclosure has been conducted in low and middle income countries (Li *et al.* 2015). A systematic review (Simoni *et al.* 2015) found only 13 disclosure intervention studies, 12 of which focused on adult disclosure while only one, the Amagugu intervention reported on here, focused on parental disclosure to children (Rochat *et al.* 2014, Rochat *et al.* 2015) Amagugu is a low intensity intervention designed to be delivered by lay counsellors in a task shifting approach. It was developed through careful formative work (Rochat *et al.* 2013), and the conceptual framework (Rochat *et al.* 2016) and evaluation which found Amagugu to be acceptable and effective at increasing parental disclosure are described in detail elsewhere (Rochat *et al.* 2013, Rochat *et al.* 2014, Rochat *et al.* 2015). The intervention led to high maternal disclosure rates (61% full disclosure with the mother using the words 'HIV', and 39% partial disclosure with the mother using the word 'virus'). An uncontrolled evaluation study found that Amagugu led to substantial decreases in maternal and child psychological morbidity, and parenting stress, and helped mothers to communicate with their children about the nature of HIV, its treatment and the possibility of illness and death (Rochat *et al.* 2014; Rochat *et al.* 2015). Children's understanding of HIV and death remains an under-researched area in epidemic regions (Rochat *et al.* 2017). Amagugu was an evaluation study with no control group; a randomised controlled trial of the intervention has recently been completed (NCT01922882).

While Amagugu has been extensively reported on, less is known about the perspectives and experiences of the mothers participating in the intervention. Understanding maternal perspectives on participation is important because there is a growing recognition that participant engagement and involvement in intervention development and evaluation can improve outcomes (Armstrong *et al.* 2013). It is argued that the successes of interventions at scale are strongly associated with the extent to which participants report feeling engaged in the intervention and consider it responsive to a clearly identifiable, relevant need. Qualitative research on participant perspectives can help researchers understand—at least indirectly—whether the intervention facilitated behaviour change in the manner conceptualised, and what facilitated or impeded its success. There is a dearth of literature on participant perspectives in health and social intervention research (Armstrong *et al.* 2013; Brett *et al.* 2014). The primary aim of this qualitative study was an in-depth exploration of HIV-infected mothers' experiences of the Amagugu intervention.

Methods

Setting

This research took place at the Africa Centre for Population Health (Africa Centre), now Africa Health Research Institute (AHRI) (www.ahri.org). The research community is predominantly rural, isiZulu-speaking and impoverished, with one peri-urban area (Tanser, Hosegood et al. 2008). HIV prevalence amongst women attending antenatal clinics was estimated at 35% in 2012 (Department of Health 2012). Prevention of Mother-to-Child Transmission services were implemented in the sub-district in 2001, and an HIV treatment and care programme providing antiretroviral therapy (ART) through public health facilities, was introduced in 2004 (Houlihan *et al.* 2010).

Sample

In this qualitative study (Mkwanazi *et al.* 2015), we purposely recruited a sub-sample of twenty HIV-infected women, who were part of the larger Amagugu intervention evaluation (2010–2012) of 281 HIV-infected women and their HIV-uninfected 6–10-year-old children (Rochat *et al.* 2014). To be eligible to participate in this qualitative study the women had to have been tested for HIV during pregnancy (Mkwanazi *et al.* 2008) as part of the Vertical

Transmission Study (VTS) (Bland, Coovadia et al. 2010) and to have participated in Amagugu.

Sample size and selection

The sample size was determined by the time and resources available, and the expectation of reaching saturation with an estimated sample of 20–30 mothers (Mason 2010). Geographical area served as the main selection criteria to ensure participation of mothers across a variety of settings within the research population. The 20 women were purposely selected from nine geographic areas representing both peri-urban and rural settings. While mothers were purposely selected to represent all geographic areas, within each geographic area the mothers selected for the qualitative interview were randomly selected from the pool of mothers available. The researcher, using a list of participant identifiers (IDs), selected each tenth participating ID—by area—using a round robin technique until 20 participants had been selected across all areas. After completion of the 20 interviews a preliminary round of data analysis was undertaken, and the authors concluded that saturation had been reached, and no further mothers were recruited.

The Amagugu intervention

The intervention included six home-based counselling sessions, led by a lay-counsellor. The counsellor provided the mother with specifically designed age-appropriate materials and tools to use during disclosure with the child. The counsellor did not intervene directly with the child; instead they provided training and support to the mother who then disclosed to her child independently. The sessions and the conceptual framework by which each session contributes towards disclosure are summarised in Figure 1, and a detailed description of the intervention is available in open access elsewhere (Rochat *et al*. 2016). By completion of the Amagugu intervention 170 (61%) women had fully disclosed their HIV status to their children using the words 'HIV' and 110 (39%) had partially disclosed their HIV status using the words 'virus' or 'illness'(Rochat *et al*. 2014; Rochat *et al*. 2015).

Data collection

The first author, a PhD candidate who is isiZulu speaking and from the local area, contacted each participating mother by phone and scheduled an appointment for a home visit to explain the study and invite participation. At this home visit the researcher obtained written consent, and immediately completed the semi-structured interview. The semi-structured interview guide addressed specific questions regarding women's participation in the Amagugu intervention and their experiences of using the disclosure materials. All 20 women who were contacted and approached agreed to participate, and granted permission for the interviews to be audio-recorded. Interviews took place in the women's homes, two months after completion of the Amagugu study, and each woman was interviewed once for approximately one hour. The first author also took extensive notes of non-verbal cues, and observed the home surroundings during the interviews, to inform the interpretation of the results.

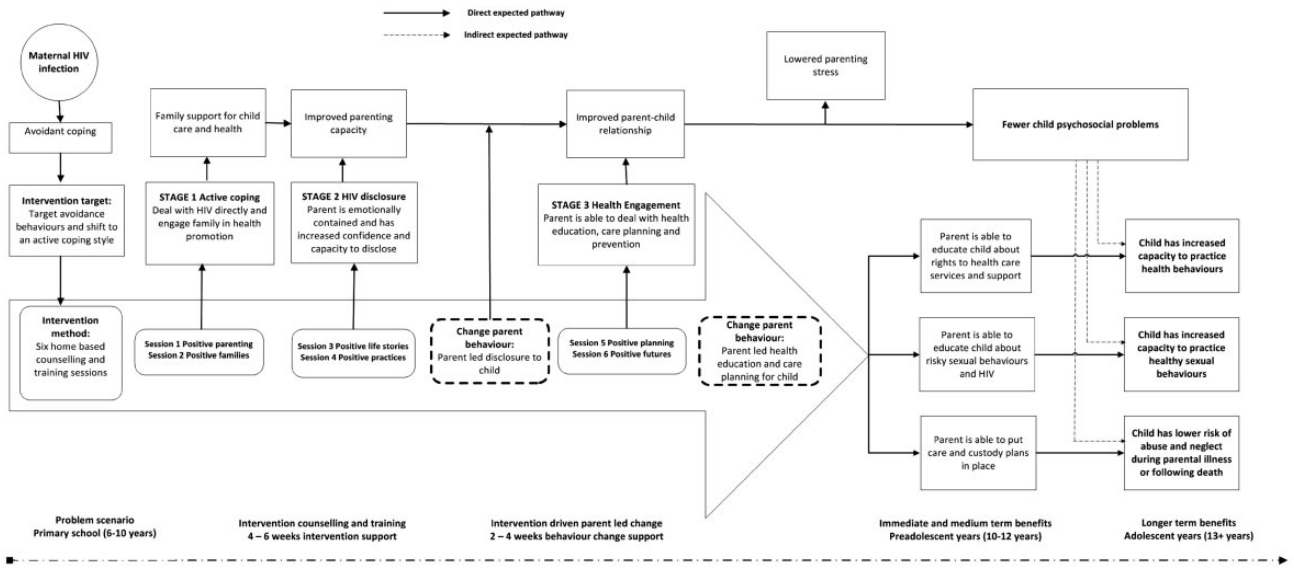

Figure 1. Outline of the home-based sessions in the Amagugu Intervention with expected behaviour change paths (Rochat *et al*. 2016)

1. What were your initial thoughts when you were first informed about the maternal HIV disclosure intervention?
2. What made you decide to take part in the HIV disclosure intervention?
3. Please take me through your Amagugu experience; what do you think worked for you and what do you think did not work for you?
4. Did you choose to fully disclose or partially disclose your status as part of the intervention?
5. Please share your thoughts on the disclosure materials that you were provided with to help you during the disclosure process
6. What do you think are the important lessons that you learned during the disclosure intervention?
7. If giving advice to another HIV-infected mother who has not disclosed to her child, about disclosure, what would your advice be?

Figure 2. Interview guide

Data triangulation

Additional data were available and extracted (with participant consent) for each woman participating in the qualitative study from the main Amagugu database, including socio-demographic data collected at baseline in the Amagugu study. Data collected post-disclosure on what the women enjoyed most about the intervention were extracted from a post-disclosure interview which was part of the Amagugu study. Using the semi-structured interview guide, content areas, including motivations for participating in the intervention, whether mothers perceived the intervention to be valuable and relevant, their views on the intervention package, and children's reactions following disclosure, were explored.

Ethical considerations

The study was approved by the relevant institutions." with lines 97-99 on page 8, "The study was approved by the Biomedical Ethics Committee of the University of KwaZulu-Natal (BF 144/010) and the Human Research Ethics Committee of the University of Witwatersrand (R14/49).

Data analysis

The first author (NM) transcribed the audio-recordings verbatim and translated them from isiZulu to English. To familiarise herself with the data NM listened to the audio-recordings, read and re-read the transcripts several times (Burnard 1991), and developed a code list derived from the literature. After a thorough review of all data, the two co-authors independently generated their own code lists. Preliminary findings were presented and discussed amongst the three authors in an analysis meeting. The three code lists were discussed, reviewed to reach consensus and the final list was adjusted accordingly to reflect the thematic areas identified.

Each mother's data were organised to reflect her specific content areas based on responses to questions in the interview guide. NM then studied the content of the transcripts looking for patterns within data chunks across all women linked to each of the specific questions in the interview guide and the thematic areas raised by the mothers in response to these questions. The coding approach was deductive, based on the interview questions in the guide which were developed to cover common areas in the patient engagement literature. In reviewing the data the researchers made an exhaustive code list of all the participants' responses. This list was then summarised into a code book which was used to code all the transcripts and make comparisons across the participants to determine which experiences were common for most of all participants. A further data analysis meeting was convened and consensus reached on the main research findings.

Results

Table 1 shows socio-demographic information of mothers and their children. The median age of the women was 32 years (IQR 29-37) and of the children seven years (IQR 6.5-7.5). There were substantially more girl children in the sample (girls 13: boys 7), and mothers had predominantly undertaken full disclosure to the child as part of the intervention (full 16: partial 4). Almost all women (18/20) reported being in stable partnerships, half were living with their partners (9/18), and disclosure to partners was high (13/18). Most women were unemployed (14/20) and had attended at least some secondary school. The majority of mothers were on ART. When comparing these characteristics to those of the larger sample of Amagugu mothers, apart from the over-representation of girl children and mothers who had undertaken full disclosure, we did not find noticeable differences between characteristics of this sub-sample and the larger Amagugu study group.

Following coding and counting, three categories of content areas were identified:

1. Barriers to disclosure prior to intervention
2. Facilitation of behavioural change towards disclosure
3. Satisfaction with the intervention package and unmet intervention needs

We present data for each of these categories, below.

Table 1. Characteristics of mothers and their children ($N = 20$)

Study ID	Maternal age (Years)	Child age (Years)	Child sex	Marital status	Employment status	Length of time on ART in years	Last CD4 cell count results cells/ml	Type of disclosure to child	Disclosed to current partner	Lives with current partner
1	26	7	F	No current partner	Unemployed	4	105	Partial	No	No
2	32	6	M	Current partner	Unemployed	1	568	Full	Yes	No
3	32	7	F	Current partner	Employed	Not on ART[a]	379	Full	No	Yes
4	44	8	M	Current partner	Employed	7	800	Full	Yes	Yes
5	46	7	M	Current partner	Unemployed	6	700	Full	Yes	Yes
6	36	6	F	Current partner	Employed	1	297	Full	Yes	Yes
7	37	7	M	Current partner	Unemployed	5	487	Full	Yes	Yes
8	49	8	F	Current partner	Unemployed	6	219	Full	Yes	No
9	28	6	F	Current partner	Unemployed	1	212	Partial	Yes	No
10	39	8	F	Current partner	Employed	2	467	Full	Yes	Yes
11	28	7	F	Current partner	Unemployed	Not on ART	629	Full	Yes	No
12	32	7	M	Current partner	Unemployed	2	518	Full	Yes	Yes
13	37	7	M	Current partner	Unemployed	1	400	Partial	No	No
14	38	6	F	Current partner	Employed	Less than 1 year	350	Full	Yes	No
15	31	8	F	Current partner	Unemployed	Not on ART	709	Full	No	No
16	36	7	F	Current partner	Employed	Not on ART[a]	459	Full	Yes	Yes
17	28	6	F	Current partner	Unemployed	Less than 1 year	300	Full	No	No
18	29	8	M	Current partner	Employed	Not on ART[a]	370	Full	No	No
19	32	7	F	No current partner	Unemployed	Not on ART	540	Partial	No	No
20	29	7	F	Current partner	Unemployed	3	394	Full	Yes	Yes

[a]At the time of the study the cut-off for ART initiation was CD4+ T-cell count ≤ 350 cells/mm^3.

Category 1: Barriers to disclosure prior to intervention

We summarised the codes reflecting what the mother reported had prevented them from disclosing prior to the intervention (disclosure barriers) along with the codes for aspects of the intervention (facilitators) which the mothers reported motivated and facilitated their change towards child disclosure as part of the intervention.

Child's developmental capacity: *n* = 11

The most common barrier that prevented disclosure prior to the intervention was related to children's developmental capacity, in particular their ability to contain information disclosed to them.

> *There was that question in the beginning, that how can you tell such a young child about that? I told their father about Amagugu and he said, how can you tell a child that? But I said let's do it!* (44 year-old mother of an 8 year-old boy).
>
> *I had told myself that I would disclose to my children when they were older and when I was sick. I have two children including a boy who is 15 years old and a 7-year old girl. I thought she was too young and even the boy I thought I was going to hurt him* (29 year-old mother of a 7 year-old girl).

HIV-related stigma *n* = 6

More than a quarter of mothers cited fear of HIV-related stigma, which included worrying that the child may disclose to others, view the mother differently, or would be stigmatised themselves, as a reason they had not disclosed to their children prior to the intervention.

> *I could not bring myself to tell her because I feared that she would go around telling other people* (49-year-old mother of an 8 year-old girl).
>
> *When the counsellor came and told me about telling my child about my HIV status I told her that I cannot tell my child about HIV because she is talkative* (26-year-old mother of a 7 year-old girl).

Protective of child (*n* = 2)

A minority of women perceived their children to be too sensitive to handle their mothers' HIV information and therefore wished to protect them emotionally.

> *As I said it was not easy because I knew it was going to sadden him…I don't think I was going to tell them. Oh! I was going to say I will wait until they were older, but then again, it was going to be more difficult when they were older* (46-year-old mother of a 7-year-old boy).

Mother's capacity (*n* = 1)

One woman reported that she did not feel confident about her capacity to answer questions the child might raise during disclosure.

> *With Amagugu they really helped us because how could you disclose to your child? Where can you even start?* (31 year-old mother of an 8 year-old girl).

Category 2: Facilitators of behavioural change towards disclosure

Most women were motivated to move towards behavioural change around disclosure based mostly on the intervention approach and intervention content, materials and tools (*n* = 11/20 or 55%). Some were motivated by the supportive relationship developed with the counsellor (*n* = 5/20 or 25%); while others (*n* = 4/20 or 20%) were motivated more by pragmatism, as the intervention was considered both important and timely, and allowed flexibility in the level of disclosure that could be undertaken.

Each of these motivations is presented in greater detail below.

Behavioural change motivated by the intervention approach, content, materials and tools (n = 11)

For over half of the mothers (11/20) the intervention approach and content was the primary motivating factor in facilitating behavioural change towards disclosure. Mothers reported that the intervention approach made the task feel more manageable, and the simplicity and user- friendliness of the materials made them feel empowered to undertake disclosure.

> *The way the intervention was presented had a big impact because we first learnt and then educated our children. The materials made it easy* (31-year-old mother of an 8-year-old girl).

Mothers reported that the intervention approach also increased their confidence in their abilities to communicate more generally.

> *…What I was taught at the Amagugu gave me strength. I even got tricks on how to start with things such as playing; you know just from playing, something profound comes out…. This is where this thing [Amagugu] helps because you don't just shout: 'My child I am sick!' No, you start slowly, and tell them step by step*. (39 year-old mother of an 8 year-old girl).

The mothers' favourable perspectives on the intervention content were reinforced by their children's positive responses to the intervention. This served to solidify that disclosure was a positive step, resulting in healthy parent-child interaction and communication with the child. That the intervention approach aimed to deal with HIV disclosure at a time when the parent was healthy and illness-free, in order to reassure the child, was important for mothers and children alike.

> *There were pictures and when he saw pictures he got excited. He even had questions. What he enjoyed the most was that I am healthy; when he comes from school I am here, I have cooked, and he eats and goes out to play* (44-year-old mother of an 8-year-old boy).

Behavioural change motivated by the supportive relationship with the counsellor (n = 5)

A second, but less common reason for being motivated to change disclosure behaviour was linked to the quality of the counsellor relationship, conferring trust and confidence, which was reported by 25% of mothers. These made reference to counsellor attributes which inspired a sense of trust and confidence in the intervention process. The counsellor was thus experienced as a supportive expert advisor and teacher who inspired mothers to undertake disclosure with children.

> *I learnt a lot from [the counsellor]… the way he communicated was so kind. He has love for the children and makes you feel welcome. He also taught me that you cannot underestimate children, because they know a lot* (32-year-old mother of a 7-year-old girl).

Behaviour change motivated by the practicality and flexibility of the intervention approach (n = 4)

For a slightly smaller proportion of mothers (4/20) the pragmatic nature of the intervention, and the fact that it responded to what the

Table 2. Aspects of the intervention reported as key to maternal satisfaction

Maternal satisfaction aspect	Quotations from mothers in support of maternal satisfaction
Communication ($n = 6$)	'I enjoyed that our talk brought back hope of life to me as we were talking'
	'I enjoyed telling my child about my status and *Family Life Line*'
	'I enjoyed opening up to my child about the pills I take every day'
	'I enjoyed the *Playing Cards* and their messages the most'
	'I enjoyed our *Family Life Line*'
	'I enjoyed the *Family Life Line* the most because (before this) the child did not know about her father'
HIV education ($n = 5$)	'I enjoyed the *HIV Body Map* the most'
	'I enjoyed explaining the *HIV Body Map* the most'
	'I enjoyed the *Body Map* because it helped to clarify my illness'
	'I enjoyed the *HIV Body Map* the most'
	'I enjoyed the *HIV Body Map* the most'
Child's developmental capacities ($n = 5$)	'I enjoyed that my child answered all the questions well when I confirmed that he understood'
	'I enjoyed that my child showed more HIV knowledge'
	'I enjoyed that my child easily understood what we were talking about the most'
	'I enjoyed that my child easily understood what we were talking about the most'
	'I enjoyed that my child understood what we were discussing and had sympathy for me'
Play and health promotion ($n = 4$)	'I enjoyed the *Playing Cards* and the *Story Book* the most'
	'I enjoyed the *Playing Cards* the most because my child understood the messages'
	'I enjoyed the *Playing Cards* the most'
	'I enjoyed the *Playing Cards* the most'

mother considered to be a valid need (which she had been feeling concerned about) was what motivated the mother to make behavioural change towards disclosure, rather than the counsellor relationship or the intervention approach per se.

> *Being sick without your children's knowledge, when this disease is so common, is not good. I would advise the person to sit down with children and explain the situation so that children will know* (37-year-old mother of a 7-year-old boy).

The flexibility to adjust the intervention to the level of disclosure she preferred, and being able to start with partial disclosure and move towards full disclosure over time was an important attraction in moving forward with the intervention. It allowed the mother to feel she could take steps to protect her child (for example through education about universal protections) without having to enter into full disclosure, for which she did not necessarily feel ready. Interestingly for both of these mothers, their experience of undertaking partial disclosure led them to understand that their child was already receiving education about HIV in other settings, such as at school.

> *I didn't tell her directly that I have HIV because I thought she was still young. I was not specific. I taught her about the virus but I found out that she already knew a lot* (32 year-old mother of a 7-year-old girl).
>
> *I told her that I am educating her about diseases. It is important that she does not use my toothbrush and my facecloth and to use gloves if there is blood. She told me that at school they also teach them about HIV. I did not tell her a lot of things because she is 7 years old, she is young* (26-year-old mother of a 7-year-old girl).

Category 3: Satisfaction with the intervention package and unmet intervention needs

As illustrated in Table 2, mothers reported a variety of positive experiences in relation to the intervention approach and materials package, and highlighted various aspects of the intervention that yielded satisfaction. These were coded under four categories:

> Communication ($n = 6$) These mothers stated that the increased communication and having tools to use to increase communication about health messages and family life with the child were the most satisfying parts of undertaking the intervention.
>
> Child capacity ($n = 5$) The opportunity to see the child's capacity to understand health and to understand the mother's HIV infection was the most satisfying part of undertaking the intervention with the child.
>
> HIV Education ($n = 5$) Access to, and use of, education tools about HIV as a disease (most especially the HIV body map) were the most satisfying part of undertaking the intervention with the child.
>
> Play and Health Promotion ($n = 4$) Mothers reported that the play tools, including the activities and games, were the most satisfying part of undertaking the intervention.

Beyond these aspects of the intervention and the specific intervention content, for a few women who had been ill since the intervention, the most satisfying aspect of the intervention was linked to the discovery, post-disclosure, of the child's capacity to understand HIV, to provide support, and assist them in managing their illness and adherence to medication.

> *I had boils on my breasts and I would be so hot that I would not know what to do. By 8 pm I would be so drowsy, he would ask me: 'How many pills do you take?' If I happen to fall asleep at 8 pm I would feel water spilling on me as he tried to give me pills [ARVs] in my sleep* (32 year-old mother of a 7-year-old boy).
>
> *She asks me all the time if I have taken my pills, even when they get finished she would tell me that your pills are running out. She is very supportive* (39-year-old mother of an 8 year-old girl).

All women, even those who were not ill, stated that the most beneficial aspect of disclosure was the support they received from their children after disclosure. While their original fears had been that they would be stigmatised by their children, on the contrary, most children were supportive. Mothers reported that their children assisted them with HIV medication adherence by reminding them to take their pills on time:

> *Sometimes when I am upset I go to bed early, she would come, wake me up and say: 'Mama it's 8 o'clock you have to take pills'* (36-year-old mother of a 6-year-old girl).

> *'What makes me happy is that my children are now my alarm clock. Before, they were just looking at me taking pills and they could not even ask what the pills were for. Now, even when I have gone to sleep and if they did not see me taking pills, they would wake me up and ask': 'Did you take the pills'?* (46-year-old mother of a 7-year-old boy).

One aspect which mothers raised as a challenge that was not addressed by the intervention was the general taboo in Zulu culture around intergenerational communication about sex. Mothers expressed a desire for specific guidance (and tools similar to the HIV education tools which could provide assistance) with intergenerational communication around sexual behaviour and life as children become older. Mothers highlighted this as a significant need as they expected that, in due course, the discussions about the mother's HIV might shift to exploring the mode of infection with HIV and that this provided an opportunity for parent-led sex education.

> *You know that it is hard to talk about sex with children being a Zulu. As Zulus we regard that as being disrespectful. . ..what is still difficult is an appropriate way of telling them. Yes there are other ways [of contracting HIV] but it is difficult to tell your child about sex* (46 year-old mother of a 7-year-old boy).
>
> *I wish there could be something motivating children and educating them about how to conduct themselves and be careful about [dangers] in life* (39-year-old mother of an 8-year-old girl).

Absence of questions and lack of negative reactions by children following disclosure were perceived by mothers to mean that children did not understand disclosure:

> *I am saying maybe she forgot because things were just normal after I told her, nothing changed* (32-year-old mother of a 7-year-old girl).

Despite all mothers having disclosed to their children, a few questioned the effectiveness of the 'Safety Hand' in ensuring that children maintained confidentiality.

> *You cannot trust that they will keep quiet.*
>
> *NM: Did you not use the Safety Hand?*
>
> *I did but I think he will tell other people.* (37-year-old mother of a 7-year-old boy)

Discussion

We find that our qualitative sample reflects closely the characteristics of the larger group of mothers who participated in Amagugu, except that in this sample we report an over-representation of girl children, and that more mothers had undertaken full as opposed to partial disclosure. There is some evidence in the literature (Qiao *et al.* 2011) that mothers tend to disclose to girl children prior to disclosing to boy children, linked to expectations that the girl child will assist with caregiving during periods of illness. While the larger Amagugu study did not find these gender effects (Rochat *et al.* 2014), it is important to consider that the views expressed in this research reflect those of mothers with a girl, rather than boy child. While this limits generalizability, the literature (Cluver *et al.* 2013) suggests that girl children exposed to, or affected by, HIV are particularly vulnerable, thus these results make an important contribution to understanding how to approach support for that population.

Children's supportive behaviours, including expressed affection following disclosure that are reported in this study, have also been described in the disclosure literature (Tompkins *et al.* 1999; Schrimshaw and Siegel 2002; Brackis-Cott *et al.* 2003). A significant role played by children in assisting their mothers with adherence to clinic appointments and HIV treatment is beneficial for HIV-affected families and needs to be supported.

Mothers in this study cited similar barriers to child disclosure as those highlighted in the literature. Specifically mothers were concerned about the children's developmental capacity to understand HIV (Kennedy *et al.* 2010; Madiba and Matlala 2012; Gachanja *et al.* 2014; Li *et al.* 2016), the potential negative psychological impact of disclosure on a child (Murphy *et al.* 2006; Murphy *et al.* 2013; Qiao *et al.* 2015), the potential effects of stigma particularly given the perceived inability of a child to contain information and not disclose to other people (Tiendrebeogo *et al.* 2013; Jao *et al.* 2016), and a lack of skills and confidence to undertake disclosure (Qiao *et al.* 2011). We show that for the overwhelming majority of mothers, the Amagugu intervention has a powerful mobilizing effect, minimising these barriers and shifting mothers to change their disclosure behaviour.

In the larger Amagugu study, we reported high rates of current partnerships and disclosure to current partners. We demonstrated that full disclosure to a current partner prior to the intervention was associated with full disclosure to children in the intervention (Rochat *et al.* 2014). In this sample we see similarly high rates of partnerships, disclosure to partners, and full disclosure to children. Importantly, we demonstrate here that at baseline, despite these relatively high rates of disclosure to significant adults in the mother's life, mothers had not undertaken disclosure to their children. This finding suggests that if rates of disclosure to children are to be increased, additional interventions focused specifically on supporting disclosure to children are required to overcome barriers to child disclosure (Dass-Brailsford *et al.* 2014; Edwards *et al.* 2014; Gachanja *et al.* 2014). Interventions which focus on adult disclosure alone are not likely to increase disclosure to children (Kennedy *et al.* 2015; Li *et al.* 2015).

We found that the supportive counsellor relationship played an important role in the mother's ability to engage with, and achieve, intervention success. The quality of the participant-counsellor relationship has been shown to influence outcomes in other research on home visiting programmes in southern Africa (Thurman *et al.* 2014) and this may be particularly true in communities where stigma remains high and where mothers feel isolated. Other studies report HIV-related stigma as the most common reason for non-disclosure (Letteney and LaPorte 2004; Palin *et al.* 2009; Qiao *et al.* 2015). However, research conducted in this study area illustrates that access to HIV treatment and care has significantly reduced HIV-related stigma and women feel supported by their partners and families (Evangeli *et al.* 2014; Mkwanazi *et al.* 2015).

Our results show that specific facilitators play an important role in shifting a mother's behaviour towards disclosure. Most importantly, mothers reported that the intervention approach, content, materials and tools, were the strongest facilitators in behaviour change toward disclosure. We have reported previously (Rochat *et al.* 2013) that mothers and counsellors in the pilot study highlighted the importance of the branding and presentation of the materials as central to their engagement with, what would otherwise be considered, a daunting task. Here we again demonstrate that the design of Amagugu as a user-friendly, interactive, participatory, activity-driven process, which provides age-appropriate games and activities, and makes learning about HIV a fun and engaging activity, contributes to successful engagement with disclosure (Rochat *et al.* 2016).

That the intervention content, approach and materials matter is an important finding, particularly in resource-constrained settings where the design of intervention packages may be primarily driven

by the need to keep costs to a minimum. However, it is plausible that the additional investment in materials which are colourful, engaging, practical and user-friendly, may make an important contribution to participant engagement with the intervention, and the resulting behavioural change. In the longer term, this may result in the intervention package becoming more cost effective, particularly since without this active engagement of the target population of parents, most community-based interventions aimed to enhance parenting would be ineffective (Staudt 2007).

There is substantial support in the literature on the importance of fostering participant engagement as a means to enhancing prevention and intervention outcomes (Snell-Johns *et al.* 2004). There is also substantial evidence to suggest that increased engagement is related to improvements in prevention and intervention outcomes in research (Brown *et al.* 2012). An important aspect of the Amagugu intervention, which is linked to the design of the intervention, is the flexibility with which mothers were allowed to adjust the intervention to meet their specific needs. Accommodating such variations, or allowing participant autonomy, may appear counter-intuitive to keeping intervention design simple and low cost, but we illustrate here that this removes barriers to behavioural change for participating mothers. This may serve to increase the applicability of the intervention to a wider audience of mothers with differing needs, capacities and circumstances. Further research is required to establish the cost-benefit ratios of providing a bespoke designed intervention package such as Amagugu, in a low-resource setting.

Despite mostly positive results in terms of participant engagement in Amagugu, and the additional benefits of ongoing treatment support to mothers within the family, some new challenges were raised by participating mothers that were not addressed through the intervention content and approach. There were concerns that the 'Safety Hand', a tool provided by the intervention to assist mothers to negotiate confidentiality of their HIV status with their children, was not trusted by some mothers to be effective in achieving that purpose. Absence of questions and lack of negative reactions by children following disclosure made some mothers doubt whether their children had fully understood the implications of their HIV status. Mothers also highlighted that, as children become older, the relationship between a parent and a child demands additional knowledge in dealing with issues such as sex education (Bhana *et al.* 2004; Visser *et al.* 2012). Women expressed a desire for Amagugu to be augmented with materials on sex education, including teenage pregnancy, and they requested something to motivate and educate their children about how they should conduct themselves in social situations. An age-appropriate illustrated 'Where do babies come from?' sex education storybook has been developed by the authors, and was tested as part of the randomised controlled trial of the intervention recently completed and currently being analysed.

Limitations

This study did not aim to address community stigma, however, future studies could assess the impact of maternal HIV disclosure on stigma outside the family setting. Women in this study had been exposed to two home-based interventions previously, the VTS and the Amagugu Study. Therefore, it is possible that they were more receptive to research involving their children and were more used to adhering to research procedures than other women, hence the high rates of maternal HIV-disclosure reported. It would be interesting to examine results from future studies using the same intervention materials, but enrolling HIV-infected women from the general population, who had not previously been involved in research. It is also possible that social desirability bias resulted in fewer mothers complaining about the intervention despite the researcher's assurance that this would be acceptable. In the context of poverty, participants with very little access to services and support may not feel comfortable to give negative feedback about a programme designed to support them. Due to logistical constraints and ethical complexities, children were not interviewed directly. Future studies could, and most probably should, investigate children's perspectives on maternal HIV disclosure.

Conclusion

It should not be assumed that adult disclosure will automatically lead to disclosure to children. Specific interventions are needed to support and encourage disclosure to children. The design and the practical content of the intervention, and investments in the branding and quality of materials, are the most important factors which elicit participant engagement. To a lesser extent the quality of the counselling support relationship also matters for mothers who have concerns about stigma. Providing mothers with the opportunity to engage their children in active participation about their HIV is highly satisfying to mothers, regardless of their circumstances.

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