

# Maternal HIV disclosure to young HIV-uninfected children: an evaluation of a family-centred intervention in South Africa

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**Objectives:** Sub-Saharan Africa has large populations of HIV-infected parents who need support to raise their HIV-uninfected children. This research evaluates the 'Amagugu Intervention' aimed at supporting mothers to disclose their own HIV diagnosis to their HIV-uninfected children.

**Design:** Uncontrolled pre and post-intervention evaluation.

**Setting:** Africa Centre for Health and Population Studies, South Africa.

**Participants:** Two hundred and eighty-one HIV-infected women and their HIV-uninfected children aged 6–10 years.

**Intervention:** This lay counsellor-led intervention included six sessions conducted with mothers at home, providing printed materials and child-friendly activities to support disclosure of their diagnosis.

**Main outcome measure:** The primary outcome was disclosure to the child (full, partial, none). The secondary outcomes included maternal mental health (General Health Questionnaire) and child mental health (Child Behaviour Checklist).

**Results:** One hundred and seventy-one (60%) women 'fully' disclosed and 110 (40%) women 'partially' disclosed their HIV status to their child. Women who perceived their health to be excellent were less likely to 'fully' disclose compared to those considering their health to be poorer [adjusted odds ratio 0.48 (0.28–0.95),  $P = 0.11$ ]. Compared to those not in a current partnership, those with a current partner were almost three times more likely to 'fully' disclose [adjusted odds ratio 2.92 (1.33–6.40),  $P = 0.008$ ]. Mothers reported that most children reacted calmly to 'full' (79%) or 'partial' disclosure (83%). Compared to 'partial' disclosure, 'full' disclosure was associated with more children asking questions about maternal death (18 versus 8%).

**Conclusions:** This intervention is acceptable in resource-limited settings and shows promise. Further research using a controlled design is needed to test this intervention.

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**Keywords:** disclosure, family, HIV, maternal disclosure, rural, school-aged children, South Africa

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## Introduction

Sub-Saharan Africa has one of the largest populations of HIV-infected parents globally [1]. As access to HIV treatment continues to increase in the region, growing numbers of HIV-infected parents are surviving to raise their predominantly HIV-uninfected children [2–4]. Access to treatment and growing evidence of the resilience of families and communities have allayed earlier concerns about orphaned generations resulting from an unmanaged epidemic [5–7]. However, HIV-infected parents need support to raise their HIV-exposed, but uninfected, children who face many risk factors associated with parental ill health and hospitalization [3,4,8], often compounded by stigma and a lack of adequate healthcare and support networks [9,10].

Research, mainly from developed [11,12] and some less developed settings [8,13–16], has shown that parental HIV disclosure has benefits for both parents and children. Most literature has focused on mothers reporting benefits, including improvements in maternal mental health, increased support for HIV treatment adherence and improved quality of relationship between mother and child [8,17]. For children, benefits include improvements in mental health and increased preparation for the child's future in terms of custody and care planning for emergencies [8,11,12,18].

Despite the reported benefits of disclosure, rates of disclosure remain relatively low internationally [8,17]. A cross-sectional study in South Africa [13] examined rates of disclosure to HIV-uninfected adolescents among women receiving support from HIV organizations. Forty-four per cent of children knew their mothers' HIV status, and most had been told by the mothers themselves. Barriers to disclosure included fears for the child's psychological well being, concerns about the risks of inadvertent disclosure to others if the child knew the mother's HIV status, and possible exposure to stigma.

A large body of descriptive research exists on maternal HIV disclosure to children as illustrated by several recent literature reviews [8,17,19]. The WHO recently published Guidelines on Disclosure to Children, encouraging disclosure of parental HIV status to HIV-uninfected children between the ages of 6 and 12 years of [20]. Primary school-aged children have been identified as a group with particular developmental needs around understanding and coping with parental life-threatening illnesses [21,22] that should be considered when designing interventions.

Few disclosure interventions targeting HIV-uninfected children have been designed and evaluated internationally [23,24]. Only a handful of studies have targeted mothers with primary school-aged children [23–26] and there is a dearth of research relating to disclosure within the family

context [27]. This is of concern as increased family and social support can improve treatment outcomes for women [11,12,17] and because of the large numbers of mothers in Southern Africa raising children under the age of 12 years [9].

In the United States, a maternal HIV disclosure trial targeted primary school-aged children of 88 mothers who specifically stated no intention to disclose their status. Intervention mothers were counselled on three occasions (mostly in their homes) and offered educational materials and follow-up telephone support [23]. The intervention resulted in disclosure rates of 33% in the intervention and 7% in the control groups, with children showing improvements in mental health following the intervention.

Recently, Visser *et al.* [26] developed and piloted a 40-session (15 mother, 15 child, 10 joint) intervention targeting children aged 6–10 years of HIV-infected mothers in South Africa. It aimed to increase parenting skills and resilience in children, providing mothers with information on children's HIV-related needs, including disclosure; no HIV content was discussed with the children. The intervention was piloted in a tertiary setting facilitated by Master's-level psychology students, at a central location, with transport provided. The pilot with 45 mother–child dyads showed low baseline disclosure rates (20%) and improvements in communication and increases in maternal disclosure to other adults, but not to enrolled children.

To date, most intervention studies have used resource-intensive approaches [26] and/or been tested in urban or high-income countries (HICs) [23,24]. However, these are not feasible for low and middle-income country (LMIC) settings, where, in order to have potential to be scaled up, interventions need to be locally acceptable, delivered at home, by lay counsellors or community healthcare workers, and provide a limited number of sessions. The 'Amagugu' Intervention was designed for resource-limited settings and piloted in South Africa [25]. The intervention includes six structured counselling sessions, each designed with specific content, activities and materials, delivered by a lay counsellor in the mother's home. There is no direct intervention with children, and mothers are supported to undertake disclosure independently. A pilot study with 24 families found the intervention to be both feasible and acceptable [25]. The purpose of this research was to evaluate this intervention and its effects on maternal and child mental health in a large sample of families.

## Methods

### Setting

The study was conducted at the Africa Centre for Health and Population Studies ([www.africacentre.com](http://www.africacentre.com)), South

Africa, from June 2010 to June 2012. The area is mostly rural or peri-urban, with one large township in the south.

The study area has one of the highest population-based HIV prevalence and incidence in the world [28,29]. A successful prevention of mother-to-child transmission of HIV programme, with HIV testing for all pregnant women, was implemented in 2001, followed by a decentralized HIV treatment and prevention programme, with provision of free drugs and clinical care, in 2004 [30,31].

### Participants

The intervention was conducted amongst Zulu families within the Africa Centre Demographic Surveillance Area [32]. We re-enrolled HIV-positive women who had all been part of the Vertical Transmission Study, a large HIV and infant feeding study previously conducted at the Africa Centre between 2001 and 2006 [33,34]. The women had all been tested for HIV during pregnancy, made informed choices about infant feeding and been followed up with their children for 2 years after birth. Mothers had given consent to be re-contacted in the future and were retraced and invited to participate. Only women with an HIV-negative child at the end of the feeding study and aged 6–10 years at the time of this research (the index child) were approached for enrolment into this intervention. Inclusion criteria required women to be living in the study area with their child (women who migrated for work were required to be resident with the child for a minimum of two nights per week, to ensure the child had adequate support through the intervention process) and both mother and child were required to be in reasonable physical and mental health. All children enrolled were HIV-uninfected at the time of enrolment.

Following established literature, ‘full’ disclosure includes disclosure using the words ‘HIV’, whereas ‘partial’ disclosure excludes the words ‘HIV’ and instead uses words such as ‘virus’ or ‘illness’ [8]. Our pilot study found that few mothers had previously disclosed to their children [25]. If a mother had already disclosed, this was not an exclusion criterion if the mother wished to participate, because most felt that the original disclosure had been unsatisfactory.

Written informed consent was obtained from each woman at home and ethical approval obtained from the Biomedical Ethics Committee of the University of KwaZulu-Natal (BF 144/010).

### The intervention

The intervention, previously documented in detail [25], was designed in line with the UK Medical Research Council guidelines for the development of complex interventions [35]. It was counsellor-led, with six sessions conducted with the mother at home, and provided printed materials and child-friendly activities and games

to support age-appropriate disclosure. It aimed to be structured enough to ensure a developmentally-appropriate disclosure process, but flexible enough for mothers to adjust the intervention to suit their personal readiness and family needs. There were two intervention stages: a pre-disclosure stage when the counsellor worked with the mother to prepare and train her towards disclosure, and a post-disclosure stage, when the mother was counselled on health promotion and custody planning.

### Evaluation and outcome measures

This was a pre and post-intervention evaluation design to explore the feasibility of this intervention approach and examine factors associated with disclosure in this rural African context prior to designing a randomized controlled trial. The primary outcome of this research was disclosure (full, partial, none) and secondary outcomes included maternal and child mental health. At baseline, before session 1, data were collected including socio-demographic variables, HIV disclosure to partner and other adults, and children in the household, and maternal education. After session 4 and prior to session 5, a structured interview was used to enquire whether the mother had disclosed either ‘partially’, ‘fully’, or not at all. Maternal reports of the child’s initial reactions to disclosure were collected. In addition at baseline and post-intervention, maternal and child mental health was assessed using the General Health Questionnaire (GHQ12) and scored using the 0,0,1,1 method [36] and the Child Behaviour Checklist (CBCL) [37], respectively. Both these tools have been used in South Africa among HIV-affected populations [25,38–41].

### Data analysis

Data were analysed using SPSS version 21. Factors potentially associated with full disclosure of HIV were examined using univariate logistic regressions. Informed by the literature and univariate regression findings, a multivariate model was investigated with maternal socio-demographic factors (mother education), maternal health (mother CD4<sup>+</sup> cell count, mother hospitalization and mother health perception) and child characteristics (child age) in block 1 and partnership characteristics in block 2. Due to the high collinearity amongst the partnership variables, a stepwise method was applied in block 2. The effects of disclosure type on children’s reactions to the intervention were explored through a further set of logistic regressions. Finally, the effect of the intervention on child (CBCL) and maternal health (GHQ12) was examined using repeated analysis of variances (ANOVAs). There were no missing data and all continuous variables met normality criteria.

### Results

Of the 319 women who were eligible to participate, the majority (91%) agreed to enrol (Fig. 1), whereas 28 women declined.

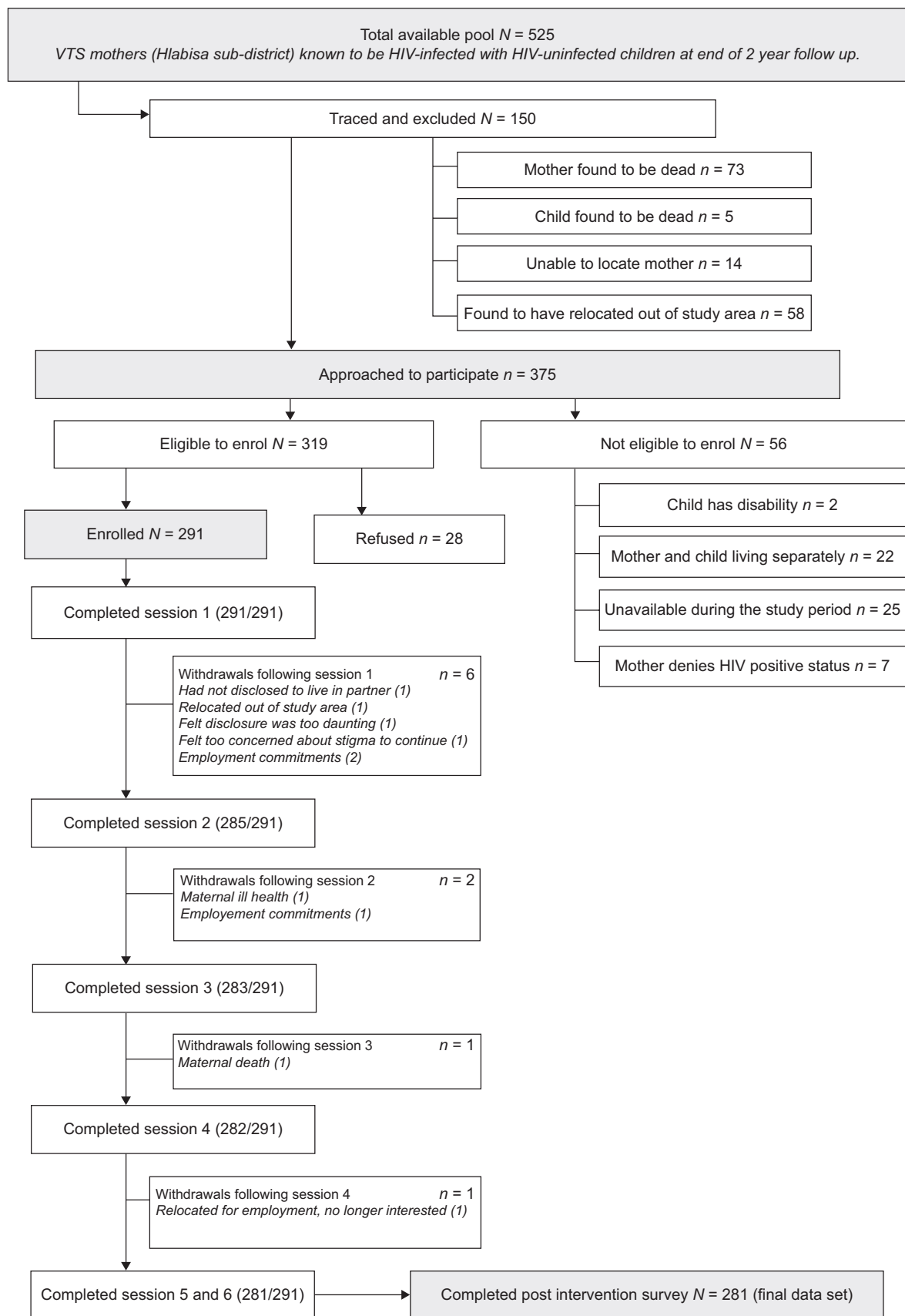


Fig. 1. Consort diagram representing women enrolled into the study.

Table 1 presents the socio-demographic background of the enrolled mothers and children. Most mothers had completed at least some secondary education, were unemployed and without a regular source of income. They were mostly in good health with almost half having a CD4<sup>+</sup> cell count above the eligibility criteria for antiretroviral therapy (ART) ( $\geq 350$  cells/ml).

The majority of mothers reported being in a current partnership, almost half (42%) with a partner who was also HIV-positive. Among women with a current partner, 70% had disclosed to their partner at baseline, of whom 97% had disclosed their status 'fully' as opposed to 'partially'. Nearly half of the enrolled mothers lived in a household with another HIV-positive adult.

### Baseline disclosure to children

At baseline, most mothers had not disclosed to any of their children under the age of 18 years. Only 26 (9%) mothers reported disclosing their status to the index child prior to the intervention, most of whom reported 'full disclosure'. Of the 255 mothers who had not previously disclosed, over half (136/155; 53.3%) stated they had no intention of disclosing to the index child as they considered the child was too young to understand the diagnosis, disclosure would negatively impact on the child emotionally, or the child might tell others outside the family. One hundred and nineteen (46.7%) mothers were willing to consider disclosure, but had not already done so as they considered it unnecessary as they were not yet sick from HIV, or were worried about who would support the child after disclosure as they were migrant workers not at home for long periods.

### Post-intervention maternal disclosure rates

After intervention, all enrolled women reported having undertaken some level of disclosure, with approximately two-thirds reporting 'full' disclosure using the words 'HIV' (Table 1).

Of those who had not previously disclosed to the index child, 62% disclosed 'fully' and 38% 'partially'. Among the seven mothers who had reported 'partial' disclosure at baseline, four reported partial, and three reported full disclosure following the intervention. Among the 19 women reporting 'full' disclosure at baseline, 12 reported 'full' disclosure after intervention, whereas 7 reported 'partial' disclosure.

### Factors associated with 'full' HIV disclosure

As shown in Table 1, few maternal or child baseline characteristics increased the odds of 'full' disclosure. Mothers who perceived their current health status to be 'excellent' were significantly less likely to 'fully' disclose compared to those who felt they were not in excellent health. Having previously 'fully' disclosed to the index child did not alter the odds of 'fully' disclosing following the intervention.

As shown in Table 2, a mother's partnership status, in particular being in a current partnership, significantly increased the odds of 'full' disclosure to the child, regardless of whether the mother was living with her current partner or not, although the current partner living elsewhere slightly increased the odds. Having disclosed to the current partner also contributed to an increase in the odds of 'fully' disclosing to the child, in particular, if the disclosure to the partner had been 'full'.

The multivariate model was significant [ $\chi^2(9) = 16.41$ ,  $P = 0.059$ ] and explained 11% of the variance of disclosure type.

### Children's reactions to disclosure

As shown in Table 3, the majority of children's reactions to disclosure were reported by the mother to be calm, regardless of whether disclosure was 'partial' or 'full'. Children whose mothers 'fully' disclosed were significantly more likely to react 'surprised' and significantly less likely to react 'confused'. Mothers who 'fully' disclosed to their children were almost five times more likely to report their child's reaction to HIV disclosure was 'emotional'.

Chi-square tests were used to examine associations between child socio-demographic variables and children's subsequent reaction to disclosure. Variables examined included children's age and sex, and both mother's and children's history of hospitalization. Among children who had a history of hospitalization, 20.9% were reported as showing a frightened reaction, whereas only 8.1% of those who had not been hospitalized were reported as frightened [ $\chi^2(1) = 6.41$ ,  $P = 0.01$ ]. No other variables were significantly associated with children's reactions to disclosure.

Maternal report indicated that children asked questions about the nature of HIV illness, transmission and treatment following disclosure, and about the possibility of maternal illness and death. Children who were 'fully' disclosed to were significantly more likely to ask questions about the possibility of maternal death. Examples of children's questions were:

Participant 31, female child, aged 6 years, following full disclosure asked: 'Why are you not sick or dead? Why are you just as pretty as you are?' Participant 71, female child, aged 7 years, following full disclosure asked: 'How long are you going to survive?' Participant 141, male child, aged 7 years, following full disclosure: 'Should I cry because you are going to die soon?' Participant 130, male child, aged 8 years, following full disclosure asked: 'How do you survive because all people suffering from HIV are dying? Are you still going to get sick? If you die of HIV who is going to take care of us?' Participant 164, male child aged 9 years, following full disclosure: 'Are the pills going to make you live long, mum? Are you not going to die, mum?'

**Table 1. Univariate and multivariate analysis of maternal and child characteristics by disclosure type.**

Maternal Characteristics	Partial disclosure (N = 110)	Full disclosure (N = 171)	Univariate		Multivariate	
			OR (95% CI)	P	OR (95% CI)	P
Age						
Median	34	35	1.00 (0.97–1.04)	0.818	–	–
Range	23–54	24–48				
Education						
No education	7 (6%)	10 (6%)	1.00		1.00	
Completed some or all primary	40 (36%)	68 (40%)	1.19 (0.42–3.37)	0.743	1.00 (0.20–4.95)	0.994
Completed some or all secondary	59 (54%)	89 (52%)	1.06 (0.38–2.93)	0.917	0.78 (0.16–3.74)	0.757
Post-school education	4 (4%)	1 (1%)	0.17 (0.02–1.92)	0.175	0.24 (0.01–4.68)	0.348
Missing	0 (0%)	3 (2%)	–	–	–	–
Employment						
Employed	40 (36%)	50 (29%)	1.00			
Unemployed	69 (63%)	119 (70%)	1.38 (0.83–2.29)	0.217	–	–
Missing	1 (1%)	2 (1%)	–	–	–	–
Regular income						
Receives regular income	25 (23%)	48 (28%)	1.00		–	–
Does not receive regular income	85 (77%)	123 (72%)	0.75 (0.43–1.31)	0.320	–	–
CD4 <sup>+</sup> cell count (most recent)						
≥501	30 (28%)	40 (23%)	1.00		1.00	
351–500	20 (18%)	33 (19%)	1.28 (0.62–2.64)	0.507	1.43 (0.64–3.15)	0.379
≤350	30 (27%)	47 (28%)	1.21 (0.63–2.34)	0.562	1.15 (0.576–2.28)	0.699
Missing	29 (26%)	51 (30%)	–	–	–	–
Hospitalization (<12 months)						
Yes	14 (13%)	16 (9%)	1.00		1.00	
No	96 (87%)	154 (90%)	1.40 (0.66–3.00)	0.383	0.67 (0.27–1.67)	0.395
Missing	0 (0%)	1 (1%)	–	–	–	–
HIV treatment status						
On ART (1)	46 (42%)	72 (42%)	1.00		–	–
Not on ART (2)	60 (55%)	95 (56%)	1.01 (0.62–1.65)	0.963	–	–
Missing	4 (3%)	4 (2%)	–	–	–	–
Perception of current health						
My health is excellent						
Not true	23 (21%)	60 (35%)	1.00	0.011	1.00	0.042
True	87 (79%)	110 (65%)	0.48 (0.28–0.85)		0.50 (0.26–0.98)	
Child characteristics						
Sex						
Female	55 (50%)	85 (50%)	1.00		–	–
Male	55 (50%)	86 (50%)	1.10 (0.63–1.63)	0.962	–	–
Age						
Median	7	7	1.14 (0.90–1.46)	0.270	1.16 (0.87–1.56)	0.310
Range	5–10	6–9				
Father still alive						
No	33 (30%)	43 (25%)	1.00		–	–
Yes	76 (69%)	127 (74%)	1.28 (0.75–2.19)	0.362	–	–
Missing	1 (1%)	1 (1%)	–	–	–	–
Father contributes financially						
Not applicable	34 (31%)	44 (26%)	1.00		–	–
Yes	45 (41%)	69 (40%)	1.18 (0.66–2.12)	0.569	–	–
No	30 (27%)	55 (32%)	1.42 (0.75–2.66)	0.279	–	–
Missing	3 (2%)	3 (2%)	–	–	–	–
Hospitalization (since birth)						
Yes	20 (18%)	23 (13%)	1.00		–	–
No	83 (75%)	138 (81%)	1.45 (0.75–2.79)	0.272	–	–
Missing	7 (6%)	10 (6%)	–	–	–	–
Prior disclosure to index child						
No	99 (90%)	156 (91%)	1.00		–	–
Yes – partial disclosure	4 (4%)	3 (2%)	0.48 (0.10–2.17)	0.338	–	–
Yes – full disclosure	7 (6%)	12 (7%)	1.09 (0.41–2.86)	0.864	–	–

CI, confidence interval; OR, odds ratio.

### Maternal mental health

Both baseline mean scores (12.32, SD = 9.83) and post-intervention mean scores (7.63, SD = 8.74) on the GHQ12 were high compared to published norms [42]. After intervention, there was a significant decrease in

GHQ12 mean scores [ $F(1, 279) = 41.32, P < 0.0001, n^2 = 0.13$ ]. Among women who ‘partially’ disclosed, pre-intervention mean GHQ12 scores were 10.9 (SD 9.26), whereas post-intervention mean scores were 7.1 (SD 7.8); among women who ‘fully’ disclosed, pre-intervention

**Table 2. Univariate and multivariate analysis of partnership characteristics by disclosure type.**

Relationship characteristics	Partial disclosure (N = 110)	Full disclosure (N = 171)	Univariate		Multivariate	
			OR (95% CI)	P	OR (95% CI)	P
Relationship status						
No current partner	27 (24%)	21 (12%)	1.00		1.00	
Current partner	83 (76%)	150 (88%)	2.32 (1.24–4.36)	0.009	2.92 (1.33–6.40)	0.008
Living with partner						
No current partner	27 (24%)	21 (12%)	1.00		–	–
Yes	35 (32%)	57 (33%)	2.09 (1.03–4.25)	0.041	–	–
No	48 (44%)	92 (54%)	2.46 (1.26–4.81)	0.008	–	–
Missing	0 (0%)	1 (1%)	–	–	–	–
Partner is HIV-positive						
Do not know partner status	35 (32%)	65 (38%)	1.00		–	–
Partner HIV-positive	34 (31%)	65 (38%)	1.03 (0.57–1.85)	0.922	–	–
Partner HIV-negative	14 (13%)	20 (12%)	0.77 (0.35–1.71)	0.519	–	–
No current partner	27 (24%)	21 (12%)	0.42 (0.21–0.85)	0.015	–	–
Partner has been disclosed to						
No current partner (3)	27 (25%)	21 (12%)	1.00		–	–
Yes (1)	56 (50%)	107 (63%)	2.46 (1.27–4.73)	0.007	–	–
No (2)	27 (25%)	43 (25%)	2.05 (0.97–4.32)	0.060	–	–
Partner disclosure level						
No partner or no disclosure to partner	54 (50%)	64 (38%)	1.00		–	–
Full disclosure (used words HIV)	53 (48%)	105 (61%)	1.67 (1.02–2.73)	0.040	–	–
Partial disclosure (used words HIV)	3 (2%)	2 (1%)	0.56 (0.09–3.49)	0.537	–	–

CI, confidence interval; OR, odds ratio.

mean GHQ12 scores were 13.1 (SD 10.1), whereas post-intervention scores were 7.9 (SD 9.3). There was no significant interaction between GHQ12 and disclosure type [ $F(1, 279) = 0.94, P = 0.334, \eta^2 = 0.003$ ].

### Child mental health

As shown in Table 4, there was a significant decrease in CBCL total scores, both internalizing and externalizing subscales, including significant decreases in anxious-depressed, withdrawn-depressed, aggressive behaviour and rule-breaking syndromes. Moderate to large effect sizes were observed. A significant moderating effect of disclosure type was revealed on withdrawn-depressed syndrome scores; thus when compared to those who fully disclosed, children of mothers who partially disclosed had a greater decrease in withdrawn-depressed syndrome scores after intervention.

### Discussion

This structured, uncontrolled, intervention was effective in helping 'their' mothers to disclose to their 6–10-year-old children. The rates of 'full' HIV disclosure are encouragingly high when compared to the existing research [8,17,19] and are higher than have been reported in other LMIC settings to date [13–16]. These results suggest that with limited structured support, mothers are willing, and able, to disclose their HIV status to their primary school-aged HIV-uninfected children, as recommended in the WHO guidelines [20].

Consistent with existing literature from developed settings we found that 'full' HIV disclosure to these younger children appeared to be associated with benefits for the children's mental health [8,17,43,44]. Since the majority of children showed mental health improvements following the intervention, regardless of disclosure type, these benefits are likely accounted for, not only by the HIV disclosure itself, but also by the broader intervention with its focus on improving parenting skills and communication with children. Results suggest for children at risk of withdrawn-depressed syndromes at baseline, the intervention was beneficial, particularly if disclosure was 'partial'. This is important as it suggests that the flexibility and choice of 'partial' or 'full' disclosure is important and should take child and family circumstances into account. This intervention focused on empowering mothers to educate, support and play with their children, and to increase the quality of their parenting and communication in their family, in general, and about HIV. This kind of intervention may provide a way to enhance the mental health of children affected by HIV.

Children's reactions to disclosure were similar to those reported in the literature [8,11,12,17], with most mothers reporting that their children reacted 'calmly'. Importantly, 'full' disclosure was associated with increased odds of children reacting 'emotionally', with discussions about possible maternal death following disclosure. Interestingly, many children asked no questions at all. Some literature has reasonably hypothesized that a lack of response or questions by children following maternal HIV disclosure may reflect their lack of understanding of the content of disclosure, possibly limited by developmental

**Table 3. Child reactions and questions following disclosure.**

Child reaction following maternal HIV disclosure	Partial disclosure (N = 110)	Full disclosure (N = 171)	Univariate	
			OR (95% CI)	P
Calm				
No	19 (17%)	35 (20%)	1.00	
Yes	91 (83%)	136 (79%)	0.81 (0.44–1.51)	0.507
Surprised				
No	92 (84%)	122 (71%)	1.00	
Yes	18 (16%)	49 (29%)	2.05 (1.12–3.76)	0.020
Confused				
No	93 (84%)	160 (94%)	1.00	
Yes	17 (15%)	11 (6%)	0.38 (0.17–0.84)	0.017
Frightened				
No	101 (92%)	152 (89%)	1.00	
Yes	9 (8%)	19 (11%)	1.40 (0.61–3.22)	0.425
Emotional				
No	108 (98%)	158 (92%)	1.00	
Yes	2 (2%)	13 (8%)	4.44 (0.98–20.08)	0.053
Child questions following maternal HIV disclosure				
HIV illness/disease				
No	92 (84%)	132 (77%)	1.00	
Yes	18 (16%)	39 (23%)	1.51 (0.81–2.80)	0.192
HIV transmission				
No	93 (84%)	144 (84%)	1.00	
Yes	17 (15%)	27 (16%)	1.02 (0.53–1.99)	0.940
Healthcare support				
No	99 (90%)	158 (92%)	1.00	
Yes	11 (10%)	13 (8%)	0.74 (0.32–1.72)	0.484
Intervention materials				
No	101 (92%)	159 (93%)	1.00	
Yes	9 (8%)	12 (7%)	0.85 (0.34–2.08)	0.717
Maternal death				
No	101 (92%)	140 (82%)	1.00	
Yes	9 (8%)	31 (18%)	2.48 (1.13–5.45)	0.023

CI, confidence interval; OR, odds ratio.

age [8,27,45,46]. However, this research suggests that not only are mothers able to disclose ‘fully’ to children as young as 6 and 7 years, but also that ‘full’ disclosure tends to elicit emotional responses and questions indicating that children do understand and grasp the HIV content of the disclosure. This research supports recommendations by other authors [10,21,27,45,46] working amongst this age group on the importance of intervening within the context of the family. Children’s persistence in questioning parents with respect to their health and HIV-related information, shown in this and previous studies [27,45,46], points to the importance of communication between mothers and children as they negotiate the disclosure process. Whereas discussions about possible maternal death may be difficult for both children and parents [14], literature suggests that it improves custody and care planning, and has practical and psychological benefits for children [8,18].

Consistent with other literature on disclosure [8], very few socio-demographic variables predicted ‘full’ disclosure to children, suggesting that the intervention itself most likely effected this change. Some literature has suggested that children’s age and sex may influence levels and rates of disclosure [11,12], but we did not find this.

One important factor – the mother’s relationship to her partner – appeared to play an important role in her decision to disclose ‘fully’ or ‘partially’ to her child. Having a current partner to whom the mother had disclosed significantly increased the odds of ‘full’ disclosure to children. This suggests that partner disclosure may be an important precursor to child disclosure, presenting opportunities to integrate partner disclosure support within broader child and family disclosure programmes. Alternatively, partner disclosure may be a proxy for increased social support, also associated with increased disclosure to children.

It is possible, given high rates of baseline partner disclosure, that mothers in this research had positive experiences of disclosing to their partners prior to this intervention. Alternatively, mothers may have felt that disclosing to their child without their partner knowing their status could itself have created difficulties. Detailed data on women’s experiences of prior partner disclosure were not collected in this research, so this could not be fully explored. It is also plausible that high child disclosure rates in this research may have been influenced by the length of time since the mother’s HIV diagnosis. All women in this study had learnt their HIV diagnosis during pregnancy, at least 6–8 years prior to this research.



Table 4. Significant intervention effects on child pre and post intervention Child Behaviour Checklist scores.

	Pre-intervention M (SD)		Post-intervention M (SD)		Intervention effect alone	Intervention by disclosure type
	Partial	Full	Partial	Full		
	CBCL total	51.56 (25.01)	42.78 (27.54)	31.21 (25.31)		
Internalizing	10.81 (7.18)	8.35 (7.28)	7.60 (6.84)	5.45 (6.18)	F (1, 279) = 73.43, P < 0.0001, $\eta^2 = 0.21$	F (1, 279) = 0.19, P = 0.659, $\eta^2 = 0.001$
Externalizing	12.83 (9.08)	10.43 (9.62)	8.59 (9.51)	6.30 (8.06)	F (1, 279) = 85.53, P < 0.0001, $\eta^2 = 0.23$	F (1, 279) = 0.01, P = 0.905, $\eta^2 = 0.001$
Anxious-depressed	5.09 (3.59)	4.24 (3.95)	3.56 (3.36)	2.54 (3.04)	F (1, 279) = 64.20, P < 0.0001, $\eta^2 = 0.19$	F (1, 279) = 0.19, P = 0.665, $\eta^2 = 0.001$
Withdrawn-depressed	2.76 (2.56)	1.71 (2.05)	1.97 (2.39)	1.45 (2.11)	F (1, 279) = 15.27, P < 0.0001, $\eta^2 = 0.05$	F (1, 279) = 3.70, P = 0.055, $\eta^2 = 0.01$
Aggressive behavior	9.63 (6.77)	7.65 (7.03)	6.40 (6.99)	4.85 (5.97)	F (1, 279) = 84.56, P < 0.0001, $\eta^2 = 0.23$	F (1, 279) = 0.43, P = 0.510, $\eta^2 = 0.002$
Rule-breaking	3.02 (2.95)	2.51 (2.95)	2.18 (3.07)	1.44 (2.52)	F (1, 279) = 32.00, P < 0.0001, $\eta^2 = 0.10$	F (1, 279) = 0.44, P = 0.507, $\eta^2 = 0.002$

CBCL, Child Behaviour Checklist; M, Mean.

Similarly, women’s participation in the original Vertical Transmission Study may have influenced their decision to enrol and to disclose in this research. Further, one of the limitations in the current literature on maternal HIV disclosure to children is the exclusion of children themselves, and reliance on maternal reports [13], with some evidence suggesting that children’s reports of their experiences may differ from those of their mothers [10,27,45]. Ethical limitations prevented direct interviewing of children in this research; however, further research which deepens our understanding of children’s experiences of disclosure, from their own perspective, is needed.

The most important limitation of this research was that this evaluation had no control group. Further, it is not possible to ascertain unequivocally whether the effects seen on child mental health were the consequences of the disclosure or changes in the relationship between mother and child. This needs to be formally tested using a controlled design. In conclusion, this intervention used a relatively low-intensity lay counsellor intervention which could feasibly be scaled up in low-resource settings. A randomized controlled trial to test this intervention against the current standard of care is currently underway (R01HD07426–01).

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### Conflicts of interest

There are no conflicts of interest declared.

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