# Maternal and child psychological outcomes of HIV disclosure to young children in rural South Africa: the Amagugu intervention

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**Objectives:** Increasingly, HIV-infected parents are surviving to nurture their children. Parental HIV disclosure is beneficial, but disclosure rates to younger children remain low. Previously, we demonstrated that the 'Amagugu' intervention increased disclosure to young children; however, effects on psychological outcomes have not been examined in detail. This study investigates the impact of the intervention on the maternal and child psychological outcomes.

**Method:** This pre-post evaluation design enrolled 281 HIV-infected women and their HIV-uninfected children (6–10 years) at the Africa Centre for Health and Population Studies, in rural South Africa. The intervention included six home-based counselling sessions delivered by lay-counsellors. Psychological outcomes included maternal psychological functioning (General Health Questionnaire, GHQ12 using 0,1,2,3 scoring); parenting stress (Parenting Stress Index, PSI36); and child emotional and behavioural functioning (Child Behaviour Checklist, CBCL).

**Results:** The proportions of mothers with psychological distress reduced after intervention: GHQ threshold at least 12 (from 41.3 to 24.9%, $P < 0.001$) and GHQ threshold at least 20 (from 17.8 to 11.7%, $P = 0.040$). Parenting stress scores also reduced (Pre $M = 79.8$; Post $M = 76.2$, $P < 0.001$): two subscales, parental distress and parent–child relationship, showed significant improvement, while mothers' perception of 'child as difficult' was not significantly improved. Reductions in scores were not moderated by disclosure level (full/partial). There was a significant reduction in child emotional and behavioural problems (CBCL Pre $M = 56.1$; Post $M = 48.9$, $P < 0.001$).

**Conclusion:** Amagugu led to improvements in mothers' and children's mental health and parenting stress, irrespective of disclosure level, suggesting general nonspecific positive effects on family relationships. Findings require validation in a randomized control trial. Copyright © 2015 Wolters Kluwer Health, Inc. All rights reserved.

## Introduction

Sub-Saharan Africa has seen many advances in HIV treatment and prevention over the last decade. The scale-up of antiretroviral treatment (ART) and prevention of mother-to-child transmission (PMTCT) programmes have changed the face of HIV for HIV-infected parents and their children [1,2]. Children of HIV-infected

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mothers are now often born uninfected in areas with functioning HIV programmes, including many parts of Africa [3−6]. In this era of improved treatment access, new challenges arise, as an increasingly large population of parents are surviving, supporting families and raising children [7,8]. Families affected by HIV face many psychosocial challenges [9] and are known to have elevated psychological and social stressors [10].

Disclosure of one's own HIV status, whether to partner, children or families, not only presents many psychosocial challenges but also offers potential to increase support for oneself [11]. Available evidence [12−14] shows that disclosure of a mother's HIV status to her HIV-uninfected children results in improvements in family communication and is associated with mental health benefits for mothers, children and families. In 2011, the WHO published Guidelines on Disclosure to Children, encouraging disclosure of parental HIV status to HIV-uninfected children aged 6−12 years [11]. Despite these reported benefits, largely demonstrated in high-income countries [15], rates of disclosure remain relatively low globally [14,16] and there is a paucity of interventions appropriate to low-resource, HIV endemic settings.

Where household burden of HIV is high [17], children are likely to be socially exposed to HIV at much younger ages than in nonepidemic areas, and there is evidence that nondisclosure may have negative effects on them [14].

TRACK, a maternal disclosure intervention, was tested in a randomized controlled trial [18] in the United States with 69 families with children aged 6−12 years. The intervention comprised three home visits, telephone support and educational materials, and found that mothers were four times more likely to disclose than controls (33 vs. 7%). This indicated that interventions could target HIV disclosure with younger children and had benefits for children's mental health. However, no studies, apart from the Amagugu intervention [19], have reported on maternal HIV disclosure interventions in rural regions in Africa.

Amagugu was designed specifically for use in low-resource, endemic HIV settings, and targets young children (6−10 years) [20]. In a nonexperimental evaluation with 281 families [19], Amagugu was found to be effective in supporting maternal disclosure. Encouragingly, all mothers undertook some level of disclosure, with 61% of mothers fully disclosing their HIV status (using the words HIV), and 39% undertaking partial disclosure, without saying the words HIV. We showed general improvements in maternal mental and child mental health.

This study investigates in detail whether the intervention had effects on maternal psychological functioning, parenting stress and children's psychological functioning, and whether any effects on these outcomes were moderated by the level of disclosure.

## Materials and methods

### Setting

The research was undertaken at the Africa Centre for Health and Population Studies in KwaZulu-Natal, South Africa (2010−2012). This area has one of the highest population-based HIV prevalence rates worldwide [21,22]. Two successful HIV programmes have been rolled out: a Prevention of Mother-to-Child Transmission of HIV programme, implemented in 2001, followed by a decentralised HIV Treatment programme in 2004 [2,23]. This population has high levels of household exposure to HIV [17], wide access to ART treatment [24] and consequent improvements in life expectancy [25] and quality of life [1].

### The intervention

The 'Amagugu' intervention is documented in detail elsewhere [20] and summarized in Fig. 1, which illustrates the three intervention stages, the working hypothesis for each, along with the purpose and tools for each session. It was delivered to mothers at home and provided printed materials and child-friendly activities supporting age-appropriate disclosure. The disclosure training content addressed maternal preparation for children's emotional reactions, and questions following disclosure [20]. Although structured, the intervention was flexible enough for mothers to adjust content to suit their personal circumstances, level of readiness and family needs. Lay-counsellors did not intervene directly with children; instead, training and support were provided to the mother, to communicate with her child independently, thus enabling skills transference and parent empowerment.

The conceptual framework of this intervention is based on well established evidence that the quality of the parent−child relationship is important for children's psychological wellbeing [26]. The mother's HIV infection, and her lack of openness with the child about it, especially in HIV-endemic regions, can lead to psychological stress. By not disclosing, the mother practices a form of avoidant/passive coping, whereby stress related to the parental HIV infection is reduced through distancing from the problem, often motivated by a desire to safeguard children from psychological distress. Parents may have concerns about stigma and fear that the child may disclose to others. Even if children are not explicitly informed, they are often aware from their parents' mood or behaviour that something is wrong, or that their parents have concerns that they are not conveying [27,28]. Thus, they may blame themselves, internalize their emotions or exhibit behavioural difficulties [29]. This in turn increases pressure on the parenting role, at a
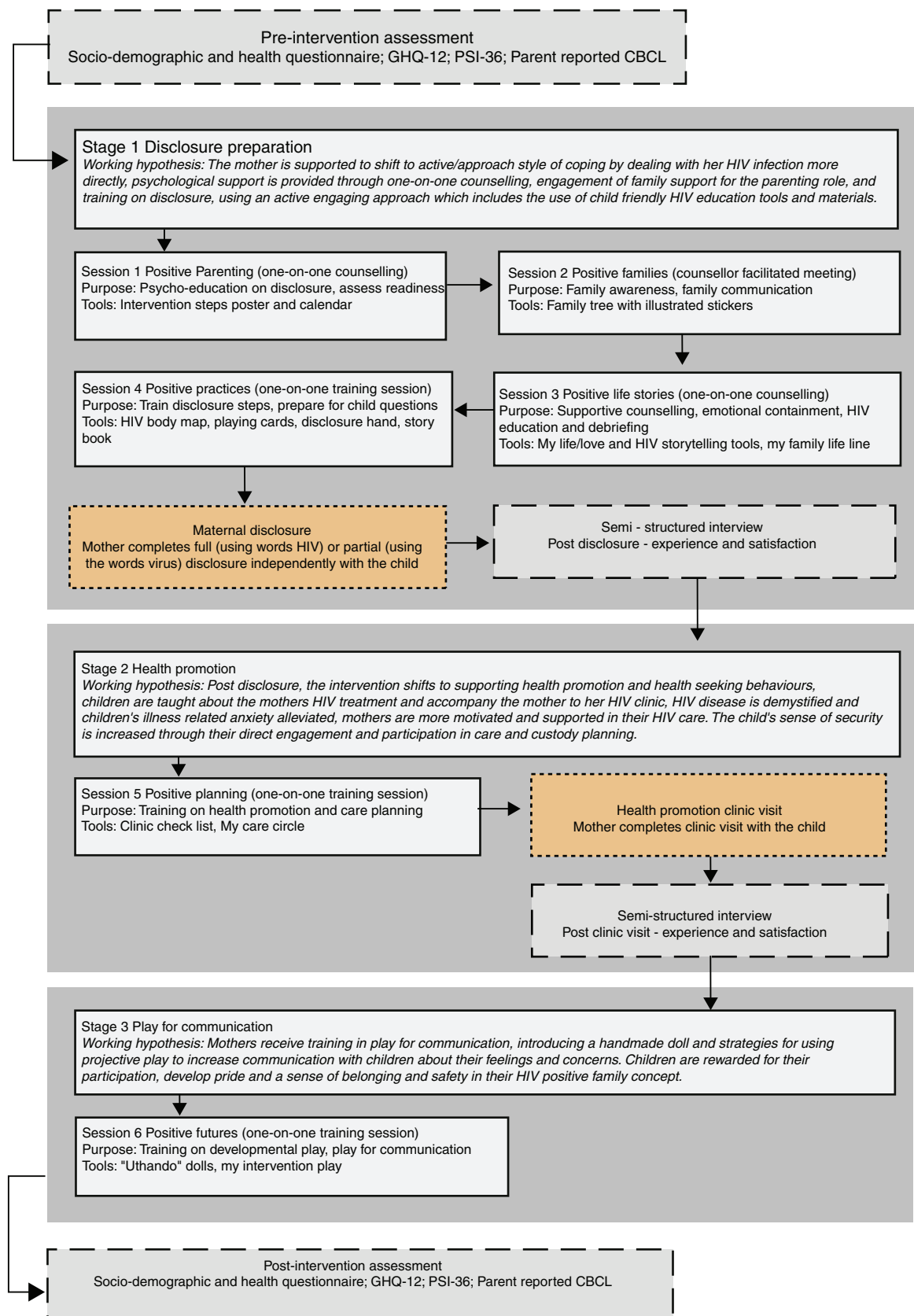
**Fig. 1.** Overview of the Amagugu intervention showing conceptual framework, session content and the timing of data collection points.

time when HIV illness and other disease-related stressors are common. The intervention supports mothers to address these challenges within the parent–child relationship and strengthens the family and healthcare support network around mother and child (see Fig. 1). The intervention shifts maternal parenting behaviours to an active coping style, provides training for disclosure, facilitates health promotion and custody planning, and trains mothers to use play to increase communication with their children. By dealing with HIV directly, the mother experiences improved mental health, lowered parenting stress and children experience less psychological distress. Through play for communication [Play for communication is adapted, with permission, from the Play for Communication Training Module designed by Dlandlanathi (http://dlalanathi.org.za/)], the quality of the parent–child relationship is strengthened.

### Counsellor selection, training and supervision

The intervention was delivered by female and male lay-counsellors, all high school graduates with several years' experience as counsellors. The 2-week training used a standardized Amagugu training manual and video, including practical exercises and competency testing. Counsellors were seen fortnightly for supervision and managed between 15 and 25 families concurrently.

### Design

This was a pre and post-intervention evaluation. Amagugu was initially tested in a small pilot study (24 families) and found to be acceptable [20]. However, there were few data available to inform larger-scale feasibility and acceptability issues, and potential risks associated with a disclosure intervention in a rural African HIV epidemic setting. A non-experimental evaluation design was chosen to explore whether this intervention approach was feasible, acceptable and increased rates of disclosure, and to examine factors associated with disclosure in the local context, prior to designing a randomized controlled trial. The design followed the guidelines for complex interventions [30] using validated measures, including multiple data collection points, and qualitative data, to inform the development of a randomized controlled trial protocol (currently underway R01HD07426-01).

### Participants

Amagugu enrolled a nested sub-sample of eligible families, all of whom had previously been part of the Africa Centre Vertical Transmission Study (VTS) [31], a large prospective HIV and infant feeding study conducted between 2001 and 2006 [32]. Women were included in the Amagugu sub-sample if they were known to be HIV-infected with an HIV-negative child at the end of VTS (see Fig. 2). VTS mothers had tested for HIV during pregnancy, received antenatal and postnatal counselling, were assessed for 2 years postnatal and consented to be recontacted for future studies. Inclusion criteria for

Amagugu further required that the VTS child was HIV-uninfected and aged 6–10 years at enrolment; mother and child were in reasonable physical and mental health; mother was living in the study area with her child, and if migrant, resident with the child for at least two nights per week, to ensure adequate support during the disclosure period. Written informed consent from mothers and assent from children was obtained. The Biomedical Ethics Committee of the University of KwaZulu-Natal (BF 144/010) gave ethics approval.

### Outcome measures

The primary outcome of the original intervention study was disclosure (full/partial/none). On the basis of guidance in the literature [14], HIV disclosure was defined as 'full' if the mother used the words HIV, or 'partial' if she described being infected with a virus, without naming HIV. Psychological outcomes included maternal psychological functioning, parenting stress and child emotional and behavioural functioning.

### Maternal psychological functioning

Maternal psychological functioning was measured using the General Health Questionnaire (GHQ-12) [33], consisting of 12 items covering the past 4 weeks, using a four-point scale (from 0 to 3). Although the scale measures depression, anxiety and social dysfunction, there is consensus that it is a unidimensional measure of psychological functioning [34]. The GHQ is not a diagnostic instrument but is used more as a screening tool.

The GHQ-12 can be scored using the GHQ weighted scoring method (0–0–1–1) [33] or the Likert weighted scoring (0–1–2–3) [35]. For this analysis, we used the Likert weighted scoring (0–1–2–3) to generate a total score ranging from 0 to 36, with higher scores indicating more psychological problems. This scoring approach is useful in research, providing a wider and smoother score distribution with which to assess severity [35,36]. The GHQ-12 has been used in Africa [37], with HIV-positive women in South Africa [38] and HIV-infected adults at the Africa Centre [39]. In this research, the GHQ-12 had good internal consistency (Cronbach's alpha pre $\alpha = 0.84$; post $\alpha = 0.88$).

Recommended cut-offs differ widely by country; in a multicountry analysis of 5438 patients [35], using Likert weighted scoring, a threshold of at least 12 produced the best sensitivity (79%) and specificity (77%) against the gold standard. Some literature recommends a higher threshold ($\geq 20$) for research on disability or chronic disease [37,40]. In this analysis, main results are presented using mean scores, and we also provide binary results using both the lower ($\geq 12$) and higher threshold ($\geq 20$) to distinguish mild from more severe distress states, in particular, as this may be informative for future intervention development [41].
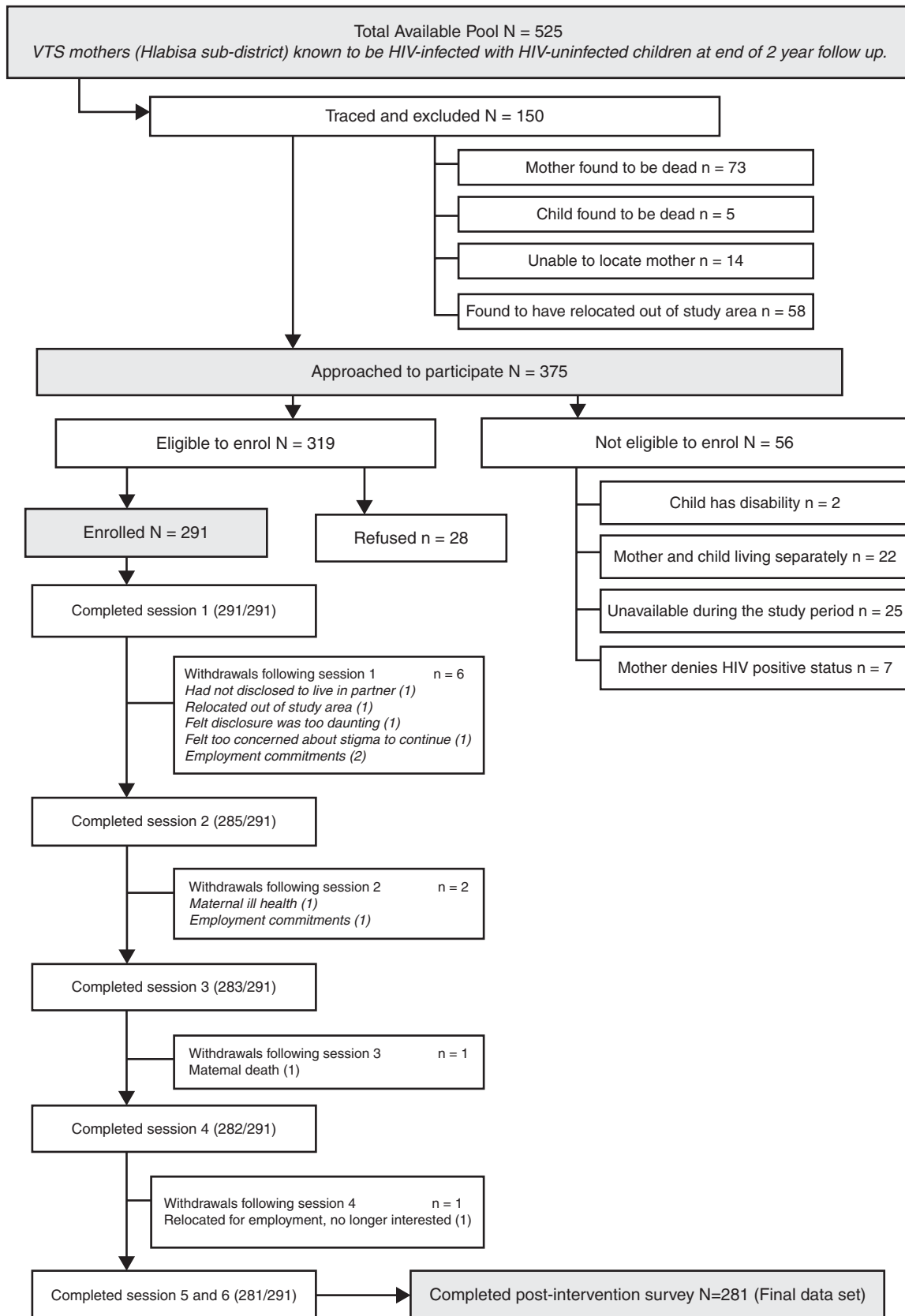
**Fig. 2. Consort diagram representing women enrolled into the study.**

## Parenting stress

Parenting stress was measured using the Parenting Stress Index, Short Form (PSI-36), a measure of stress related to parenting roles, designed for parents of children under 12 years of age [42]. It consists of 36 statements, scored 1 (strongly disagree) to 5 (strongly agree), and has three subscales of 12 items each:

(1) Parental Distress Subscale measures perceptions of parenting competence, conflict with the child's other parent, social support and depression.
(2) Parent-Child Dysfunction Interaction Subscale (P-CDI) measures the extent to which parent−child interactions are satisfying, whether the child is seen as a disappointment or the parent feels rejected by, or alienated from, the child.
(3) Difficult Child Subscale measures the extent to which the parent finds it hard to gain the child's cooperation and/or manage the child's behaviour.

Each sub-scale score ranges from 12 to 60; the PSI-36 Total Stress score is a composite score of the three sub-scales (scores range 36−180), with higher scores indicating higher parental stress [43]. The PSI-36 has been used widely internationally [44], with HIV-infected mothers in South Africa [38] and in the current research demonstrated good internal consistency (Cronbach's alpha pre $\alpha = 0.92$; post $\alpha = 0.93$).

## Child emotional and behavioural disorders

Children's emotional and behavioural functioning was measured using the parent-reported Child Behaviour Checklist (CBCL) [45]. The CBCL is a widely used measure of children's emotional and behavioural problems, validated across multiple cultural settings [46]. The researchers were granted a translation license (#512-10-29-10) and the CBCL was translated, back translated and approved by the test developers.

In this analysis, CBCL scores were normed using the multicultural rating-to-score (RTS) norming software [47] developed by the authors of the CBCL, which produce normed $t$-scores for the total score, internalizing and externalizing sub-scales and for six Diagnostic and Statistical Manual (DSM) childhood mental disorders. The CBCL has been used in South Africa [48], among HIV-affected populations [49], and achieved good reliability in the current research (Cronbach's alpha pre $\alpha = 0.94$; post $\alpha = 0.92$).

## Data analysis

Data were analysed using SPSS version 21. Missing data for individual scales were found for 20 participants (7% of data) and were imputed using the mean series for the individual participant for that particular scale. All continuous variables met normality criteria (skewness ≤1.5). One-way repeated measures (analysis of covariances, ANCOVAs) were conducted to examine the effects of the intervention and the moderating effect of disclosure type on continuous scores of maternal psychological morbidity (GHQ), parenting stress (PSI) and children's emotional and behavioural disorders (CBCL). The effects of intervention on the percentage change on the GHQ (using low ≥12 and high ≥20 thresholds) were explored through $Z$-tests for differences between proportions. Characteristics potentially associated with higher maternal psychological morbidity and parenting stress continuous scores at pre test were examined using analysis of variances (ANOVAs). Using a theoretical model developed previously [19], we examined maternal age, education, employment, income, CD4$^+$ cell count, HIV treatment status and hospitalization, and child age, sex, father involvement and prior hospitalizations.

## Results

Of an available pool of 525 VTS mothers, 136 (26%) were ineligible (death, relocation) and 14 (3%) were untraceable. Of the remaining 375 women approached to participate, 56 (15%) did not meet inclusion criteria (see Fig. 2 for reasons), while 28 (7%) refused and 291 (78%) enrolled. Amongst enrolees, 10 (3%) withdrew during the course of the study and 281 completed follow-up.

Data from a separate follow-up of VTS in 2013−2014 show that the 53 Amagugu nonparticipators (refusals and not available for participation, Fig. 2) were significantly more likely to be younger than participators (M 34.7 years; M 37.0 years, $P = 0.003$) although the mean difference was marginal. No other significant differences were found on maternal intelligence quotient (IQ), education, employment, relationship status, ART and child age or sex.

The majority of participating mothers ($n = 281$) had completed at least primary education, were on ART, had no regular income source, and were in a current partnership, many with a partner who was also HIV-positive (see Table 1).

### Maternal psychological morbidity

Using mean scores, there was a significant moderate decrease in maternal psychological morbidity mean scores, measured by the GHQ (Table 2) post-intervention. Disclosure type did not moderate intervention effects significantly.

Using the at least 12 threshold [35], we investigated whether the intervention significantly decreased the number of mothers with elevated psychological morbidity. At baseline, 41.3% mothers scored above the threshold compared with 24.9% after the intervention. This decrease was significant (see Table 2) and consistent

## Table 1. Maternal and child characteristics by postintervention disclosure level.

| Maternal characteristics | Partial disclosure ($N = 110$) | Full disclosure ($N = 171$) |
|---|---|---|
| Age (years) | | |
| Median | 34 | 35 |
| Range | 23–54 | 24–48 |
| Education | | |
| No education | 7 (6%) | 10 (6%) |
| Completed some or all primary | 40 (36%) | 68 (40%) |
| Completed some or all secondary | 59 (54%) | 89 (52%) |
| Post school education | 4 (4%) | 1 (1%) |
| Missing | 0 (0%) | 3 (2%) |
| Employment | | |
| Employed | 40 (36%) | 50 (29%) |
| Unemployed | 69 (63%) | 119 (70%) |
| Missing | 1 (1%) | 2 (1%) |
| Regular Income | | |
| Receives regular income | 25 (23%) | 48 (28%) |
| Does not receive regular income | 85 (77%) | 123 (72%) |
| CD4$^+$ cell count (most recent), cells/µl | | |
| ≥501 | 30 (28%) | 40 (23%) |
| 351–500 | 20 (18%) | 33 (19%) |
| ≤350 | 30 (27%) | 47 (28%) |
| Missing | 30 (26%) | 51 (30%) |
| Hospitalization (last 12 months) | | |
| Yes | 14 (13%) | 16 (9%) |
| No | 96 (87%) | 154 (90%) |
| Missing | 0 (0%) | 1 (1%) |
| HIV treatment status | | |
| On ART | 46 (42%) | 72 (42%) |
| Not on ART | 60 (55%) | 95 (56%) |
| Missing | 4 (3%) | 4 (2%) |
| Relationship status | | |
| No current partner | 27 (24%) | 21 (12%) |
| Current partner | 83 (76%) | 150 (88%) |
| Living with partner | | |
| No current partner | 27 (24%) | 21 (12%) |
| Yes | 35 (32%) | 57 (33%) |
| No | 48 (44%) | 92 (54%) |
| Missing | 0 (0%) | 1 (1%) |
| Partner's HIV status | | |
| Unknown status | 35 (32%) | 65 (38%) |
| HIV positive | 34 (31%) | 65 (38%) |
| HIV negative | 14 (13%) | 20 (12%) |
| No current partner | 27 (24%) | 21 (12%) |
| **Child characteristics** | | |
| Gender | | |
| Female | 55 (50%) | 85 (50%) |
| Male | 55 (50%) | 86 (50%) |
| Age (years) | | |
| Median | 7 | 7 |
| Range | 5–10 | 6–9 |
| Father still alive | | |
| No | 33 (30%) | 43 (25% |
| Yes | 76 (69%) | 127 (74%) |
| Missing | 1 (1%) | 1 (1%) |
| Father contributes financially | | |
| Not applicable | 34 (31%) | 44 (26%) |
| Yes | 45 (41%) | 69 (40%) |
| No | 30 (27%) | 55 (32%) |
| Missing | 2 (2%) | 3 (2%) |
| Hospitalization (since birth) | | |
| Yes | 20 (18%) | 23 (13%) |
| No | 83 (75%) | 138 (81%) |
| Missing | 7 (6%) | 10 (6%) |

ART, antiretroviral therapy.

across disclosure types with rates decreasing amongst those who fully and partially disclosed. Using the 'at least 20' threshold [40], a similar pattern was observed, 17.8% of mothers preintervention, compared with 11.7% post-intervention. Moderation was not investigated for the high threshold because of small cell counts.

## Parenting stress

Using continuous scores, PSI total mean scores post-intervention were lower than pre-intervention (Table 3). This decrease was not significantly moderated by disclosure type. PSI sub-scales showed significant decreases from pre to post-intervention for the PSI-Parental Distress and the PSI Parent-Child sub-scales, with no significant disclosure type moderation, but no significant changes on the PSI-Difficult Child sub-scale.

## Association between baseline characteristics, psychological functioning and parenting stress

As described in the Materials and methods section, maternal and child characteristics were investigated as predictors of maternal psychological functioning at baseline. Results revealed a significant effect of increased maternal age ($r = 0.13$, $P = 0.026$) and employment status on GHQ scores with unemployed mothers reporting higher scores [employed $M = 9.73$ (SD $= 6.75$); unemployed $M = 12.10$ (SD $= 8.43$); $F(1, 276) = 5.40$, $P = 0.021$, $\eta_p^2 = 0.02$]. Likewise, compared with those with no income, those with access to income had lower mental health risks [income $M = 9.68$ (8.11); no income $M = 12.05$ (8.05), $F(1, 279) = 4.66$, $P = 0.032$, $n^2 = 0.02$]. Mothers who were not in a relationship displayed higher scores than those in a relationship [relationship $M = 10.95$ (SD $= 7.76$), no relationship $M = 13.79$ (SD $= 9.40$); $F(1, 279) = 4.94$, $P = 0.027$, $\eta_p^2 = 0.02$], and scores of mothers who were on ART were significantly higher than those of mothers not on ART [on ART $M = 13.69$ (SD $= 8.51$), not on ART $M = 9.58$ (SD $= 7.46$); $F(1271) = 18.03$, $P < 0.001$, $\eta_p^2 = 0.06$]. No child characteristics were significantly associated with maternal psychological functioning, although child hospitalization in the past 12 months showed borderline significance [Hospitalization $M = 13.30$ (9.24), no hospitalization $M = 10.75$ (7.66), $P = 0.054$].

For parenting stress, maternal education had a significant effect on PSI scores [$F(3, 274) = 3.08$, $P = 0.028$, $\eta_p^2 = 0.03$]. Posthoc analyses revealed that mothers with no education or education only to primary school level ($M = 83.15$, SD $= 22.03$) reported higher levels of stress ($P = 0.010$) than those who completed some or all secondary schooling ($M = 76.11$, SD $= 20.36$). Unemployment was related to higher stress scores [$F(1276) = 6.57$, $P = 0.01$, $\eta_p^2 = 0.02$; employed $M = 74.81$ (SD $= 21.01$), not employed $M = 81.78$ (SD $= 21.31$)].

**Table 2. Pre and post-intervention General Health Questionnaire continuous score and ≥12 and ≥20 thresholds.**

| | Pre-intervention $M$ (SD) | | | Post-intervention $M$ (SD) | | | Intervention effect alone | Intervention by disclosure type |
|---|---|---|---|---|---|---|---|---|
| | Partial | Full | Total | Partial | Full | Total | | |
| GHQ Continuous | 10.35 (7.73) | 12.14 (8.30) | 11.44 (8.12) | 7.10 (6.76) | 8.12 (8.28) | 7.72 (7.23) | $F(1, 279) = 40.06$, $P < 0.0001$, $\eta_p^2 = 0.13$ | $F(1, 279) = 0.46$, $P = 0.50$, $\eta_p^2 = 0.002$ |

| | Pre-intervention proportion ≥threshold $n$ (%) | | | Post-intervention proportion ≥threshold $n$ (%) | | | Intervention effect alone $(z)P$ | Intervention by disclosure type $(z)P$ |
|---|---|---|---|---|---|---|---|---|
| | Partial | Full | Total | Partial | Full | Total | | |
| GHQ ≥12 | 38 (34.5%) | 78 (45.6%) | 116 (41.3%) | 23 (20.9%) | 47 (27.5%) | 70 (24.9%) | $Z = 4.12$, $P < 0.001$ | Partial $Z = 2.26$, $P = 0.020$; Full $Z = 3.48$, $P < 0.001$ [a] |
| GHQ ≥20 | 12 (10.9%) | 38 (22.2%) | 50 (17.8%) | 8 (7.3%) | 25 (14.6%) | 33 (11.7%) | $Z = 2.02$, $P = 0.040$ | |

GHQ, General Health Questionnaire. [a]Moderation was not tested for GHQ ≥20 due to small cell size.

**Table 3. Pre and post-intervention General Health Questionnaire and parenting stress scores.**

| | Pre-intervention $M$ (SD) | | | Post-intervention $M$ (SD) | | | Intervention effect alone | Intervention by disclosure type |
|---|---|---|---|---|---|---|---|---|
| | Partial | Full | Total | Partial | Full | Total | | |
| PSI total | 77.10 (23.00) | 81.61 (20.8) | 79.84 (21.80) | 73.66 (23.45) | 77.90 (21.86) | 76.24 (22.55) | $F(1, 279) = 12.89$, $P < 0.0001$, $\eta_p^2 = 0.04$ | $F(1, 279) = 0.02$, $P = 0.89$, $\eta_p^2 = 0.001$ |
| PSI parent–child | 23.03 (8.64) | 24.15 (6.83) | 23.71 (7.59) | 22.12 (9.11) | 22.46 (8.05) | 22.33 (8.46) | $F(1, 279) = 7.47$, $P = 0.007$, $\eta_p^2 = 0.03$ | $F(1, 279) = 0.67$, $P = 0.41$, $\eta_p^2 = 0.002$ |
| PSI distress | 29.55 (10.60) | 31.22 (9.83) | 30.57 (10.15) | 27.23 (10.60) | 29.17 (10.72) | 28.41 (10.69) | $F(1, 279) = 12.56$, $P < 0.0001$, $\eta_p^2 = 0.04$ | $F(1, 279) = 0.05$, $P = 0.81$, $\eta_p^2 = 0.001$ |
| PSI difficult child | 24.51 (7.66) | 26.25 (7.52) | 25.57 (7.61) | 24.32 (26.27) | 26.27 (7.38) | 25.51 (7.47) | $F(1, 279) = 0.23$, $P = 0.63$, $\eta_p^2 = 0.001$ | $F(1, 279) = 0.38$, $P = 0.54$, $\eta_p^2 = 0.001$ |

## Child psychological functioning

As summarized in Table 4, a marked effect size was observed in the CBCL standardized total score. The magnitude of effects observed in the internalizing and externalizing sub-scales was comparable. Significant decreases were observed across all CBCL scales with children showing 2−4 points decrease in the DSM-orientated sub-scales. The strongest observed effects were on the Conduct and Oppositional DSM sub-scales, although the effects were smallest on the Attention Hyperactivity Deficient Disorder (ADHD) sub-scale. None of these effects were moderated by disclosure type.

## Discussion

HIV-infected mothers, living in low-resource settings with a limited access to support and services [50], face multiple challenges coping with the stress of caring for their children and living with a chronic, potentially life-threatening disease [51]. In this research, mothers who were unemployed with no access to regular income, not in a partnership, and not on ART had higher mental health risks at baseline. Increasing evidence suggests that adults living with HIV are vulnerable to mental health difficulties [52] that impact on their health outcomes [53] and their ability to care for their children [10,54]. Similarly, parents with chronic health problems, such as HIV, have been shown to have higher levels of parenting stress, which affects their parenting capacity [55,56]. There is an urgent need for culturally acceptable, scalable, low-intensity psychosocial support interventions for this growing population of parents in Africa.

The intervention resulted in high rates of disclosure, and also resulted in significant decreases in maternal and child psychological morbidity and parenting stress. This is important, as avoidant coping has been shown to play a negative role in parenting in other research in South Africa [56] and could impact negatively on adherence behaviours. It is plausible that the decreases in parenting stress may be linked to increases in disclosure, and the concomitant decreases in avoidant coping.

The link between parental mental health, parenting behaviours and child outcomes is well established [57,58], with children of depressed, anxious or highly stressed mothers known to be at an increased risk of psychological, educational and behavioural problems [56,59,60]. Our findings demonstrate significant overall improvements in maternal psychological functioning, as measured by the GHQ, with mean scores decreasing substantially pre-post regardless of disclosure level. This is an important finding, not only because of established benefits for children but also because improvements in mental health symptoms have been shown to have a significant impact on improved HIV treatment adherence [61].

It is of interest that the intervention effect on maternal mental health appeared to be stronger for women who scored above the GHQ threshold of at least 12, than for those at the higher threshold ($\geq$20) at baseline. Although the women with high levels of psychological morbidity do show improvements, it is likely that they require therapeutic interventions that Amagugu did not provide because it is not designed as treatment for clinical depression or anxiety, for which more established therapeutic interventions exist [62,63]. This is important given recent calls to advance intervention science through a better understanding of the distinction between milder distress states (which can be successfully addressed through low-intensity psychosocial support models delivered by lay professionals, such as Amagugu) from probable clinical level distress requiring specialist healthcare interventions [41].

A recent systematic review on HIV-affected children [10] found that preadolescent children affected by HIV were at an increased risk of internalizing and externalizing problems, noting however that almost no research has been conducted with primary school aged children in Africa, and highlighting the scarcity of interventions that may ameliorate these effects for HIV-affected children in low- and middle-income countries (LMICs). Therefore, our finding that the intervention had significant positive effects on children's psychological wellbeing suggests that this age group can benefit from these kinds of intervention.

Although the mean CBCL scores were below the clinical threshold at baseline, there were significant reductions following intervention. Improvements were most substantial on oppositional and conduct disorders and there was a considerable improvement on somatic scores. In other LMIC settings, somatization has been associated with later depression and anxiety in children [64,65], and in Europe and the United States, early conduct problems predict poor behaviour and educational outcomes in adolescents and adults [66]; hence, improvements in these domains may have preventive benefits for children.

Notably, within the Parenting Stress Index, although parental distress and the parent−child relationship were significantly improved, parental perceptions of their child being difficult were not. Another parenting intervention in South Africa has also found that aspects of parental stress persist despite improvements in parental reports of children's behaviour [56]. More sociocultural research is needed to better understand parent perceptions of children's difficult behaviours, although factors associated with parenting stress at baseline (low education, unemployment) are similar to those in the literature [67]. Parents who find it difficult to gain their child's

**Table 4. Pre and post-intervention Child Mental Health scores.**

| | Pre-intervention M (SD) | | | Post-intervention M (SD) | | | Intervention effect alone | Intervention by disclosure |
|---|---|---|---|---|---|---|---|---|
| | Partial | Full | Total | Partial | Full | Total | | |
| Total | 59.44 (9.98) | 53.98 (13.14) | 56.12 (12.28) | 51.99 (13.08) | 46.89 (13.55) | 48.89 (13.57) | $F_{(1, 279)} = 148.85$, $P < 0.0001$, $\eta_p^2 = 0.35$ | $F_{(1, 279)} = 0.09$, $P = 0.76$, $\eta_p^2 \leq 0.0001$ |
| Internalizing | 58.98 (10.09) | 54.32 (11.70) | 56.15 (11.31) | 53.55 (10.78) | 48.97 (11.23) | 50.77 (11.26) | $F_{(1, 279)} = 88.86$, $P < 0.0001$, $\eta_p^2 = 0.24$ | $F_{(1, 279)} = 0.004$, $P = 0.95$, $\eta_p^2 = 0.0001$ |
| Externalizing | 59.67 (11.02) | 54.93 (13.23) | 56.79 (12.61) | 52.84 (12.77) | 49.01 (12.69) | 50.51 (12.83) | $F_{(1, 279)} = 107.14$, $P < 0.0001$, $\eta_p^2 = 0.28$ | $F_{(1, 279)} = 0.55$, $P = 0.46$, $\eta_p^2 = 0.28$ |
| DSM-orientated subscales | | | | | | | | |
| Depression | 58.72 (7.99) | 56.91 (7.55) | 57.62 (7.76) | 56.15 (7.86) | 54.53 (6.87) | 55.16 (7.31) | $F_{(1, 279)} = 34.29$, $P < 0.0001$, $\eta_p^2 = 0.11$ | $F_{(1, 279)} = 0.05$, $P = 0.83$, $\eta_p^2 = 0.0001$ |
| Anxiety | 57.21 (7.00) | 56.48 (7.47) | 56.77 (7.29) | 55.02 (6.26) | 53.53 (5.72) | 54.11 (5.97) | $F_{(1, 279)} = 36.58$, $P < 0.0001$, $\eta_p^2 = 0.12$ | $F_{(1, 279)} = 0.80$, $P = 0.37$, $\eta_p^2 = 0.003$ |
| Somatic | 60.41 (8.38) | 58.64 (9.20) | 59.33 (8.91) | 57.16 (8.17) | 55.60 (7.67) | 55.60 (7.67) | $F_{(1, 279)} = 36.64$, $P < 0.0001$, $\eta_p^2 = 0.12$ | $F_{(1, 279)} = 0.04$, $P = 0.84$, $\eta_p^2 = 0.0001$ |
| ADHD | 56.17 (6.56) | 54.87 (6.12) | 55.38 (6.31) | 54.07 (5.88) | 52.73 (4.90) | 53.25 (5.34) | $F_{(1, 279)} = 29.40$, $P < 0.0001$, $\eta_p^2 = 0.09$ | $F_{(1, 279)} = 0.003$, $P = 0.96$, $\eta_p^2 = 0.0001$ |
| Oppositional | 57.22 (7.22) | 56.08 (7.25) | 56.53 (7.25) | 54.75 (6.96) | 53.22 (5.62) | 53.82 (6.21) | $F_{(1, 279)} = 49.78$, $P < 0.0001$, $\eta_p^2 = 0.15$ | $F_{(1, 279)} = 0.27$, $P = 0.60$, $\eta_p^2 = 0.0001$ |
| Conduct | 61.45 (8.99) | 59.11 (9.65) | 60.03 (9.45) | 57.12 (9.14) | 55.34 (7.93) | 56.04 (8.46) | $F_{(1, 279)} = 73.63$, $P < 0.0001$, $\eta_p^2 = 0.21$ | $F_{(1, 279)} = 0.35$, $P = 0.55$, $\eta_p^2 = 0.0001$ |

ADHD, Attention Hyperactivity Deficient Disorder; DSM, Diagnostic and Statistical Manual.

cooperation may require education on behavioural techniques [68], which fall outside the scope of Amagugu.

The positive effects on children's psychological functioning were not moderated by the extent of disclosure, suggesting that the intervention had positive nonspecific effects on family relationships and communication. Engaging family support around parental responsibilities and offering encouragement of the important role HIV-infected parents play in their children's lives likely contributed to such improvements, as has been demonstrated in other family strengthening intervention research in Africa [69].

Lastly, the finding that Amagugu had a positive impact on both the primary outcome (maternal disclosure) and secondary intervention targets is important for two reasons: interventions targeting parental disclosure as an isolated endpoint are unlikely to be cost-effective at scale; and improving rates of disclosure without improvements in family functioning, principally parenting and parent/ mother and child mental health, is unlikely to be worthwhile. Our findings from this nonexperimental intervention are broadly in line with mental health benefits of interventions tested in HIC [18] and to higher intensity interventions that aimed to build resilience in children of HIV- infected parents in low-resource settings [70]. Mental health interventions, which do not directly help parents to deal with HIV disclosure to their children, may have disadvantages within the family context [71–73], particularly in HIV endemic regions.

Limitations of this research include that data were mother-reported; however, young children do not report reliably on their psychological symptoms, and further, it was deemed too sensitive to question the children directly, and thus adult report was used. Maternal psychological morbidity may influence mothers' reports, although there is little evidence to support this in the literature [74,75]. The main limitation is that this evaluation had no control group, hence although the changes in maternal and child mental health are plausibly attributed to the intervention, this needs to be formally tested using a randomized controlled design.

This intervention used a relatively low-intensity lay-counsellor approach feasible for scale-up in low-resource settings, which led to increased disclosure and improved mental health. If these results are replicated in a randomized controlled trial, Amagugu could provide a sustainable home-based intervention targeting families with young HIV-exposed children.

## Acknowledgements

## Conflicts of interest

The authors have no conflicts of interest to declare.

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