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Communication about HIV and death: Maternal reports of primary school-aged children's questions after maternal HIV disclosure in rural South Africa

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ABSTRACT

Introduction: Children's understanding of HIV and death in epidemic regions is under-researched. We investigated children's death-related questions post maternal HIV-disclosure. Secondary aims examined characteristics associated with death-related questions and consequences for children's mental health. **Methods:** HIV-infected mothers ($N = 281$) were supported to disclose their HIV status to their children (6–10 years) in an uncontrolled pre-post intervention evaluation. Children's questions post-disclosure were collected by maternal report, 1–2 weeks post-disclosure. 61/281 children asked 88 death-related questions, which were analysed qualitatively. Logistic regression analyses examined characteristics associated with death-related questions. Using the parent-report Child Behaviour Checklist (CBCL), linear regression analysis examined differences in total CBCL problems by group, controlling for baseline. **Results:** Children's questions were grouped into three themes: 'threats'; 'implications' and 'clarifications'. Children were most concerned about the threat of death, mother's survival, and prior family deaths. In multivariate analysis variables significantly associated with asking death-related questions included an absence of regular remittance to the mother ($AOR\ 0.25$ [$CI\ 0.10, 0.59$] $p = 0.002$), mother reporting the child's initial reaction to disclosure being "frightened" ($AOR\ 6.57$ [$CI\ 2.75, 15.70$] $p < 0.001$) and level of disclosure (full/partial) to the child ($AOR\ 2.55$ [$CI\ 1.28, 5.06$] $p = 0.008$). Controlling for significant variables and baseline, all children showed improvements on the CBCL post-intervention; with no significant differences on total problems scores post-intervention ($\beta\ -0.096$ $SE1.366$ $t = -0.07$ $p = 0.944$).

Discussion: The content of questions children asked following disclosure indicate some understanding of HIV and, for almost a third of children, its potential consequence for parental death. Level of maternal disclosure and stability of financial support to the family may facilitate or inhibit discussions about death post-disclosure. Communication about death did not have immediate negative consequences on child behaviour according to maternal report. **Conclusion:** In sub-Saharan Africa, given exposure to death at young ages, meeting children's informational needs could increase their resilience.

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1. Introduction

Many children in Africa are at risk of parental bereavement, either as a direct result of their parents' HIV infection or indirectly

through HIV-related social and health adversities (Hosegood, 2009). The effects of HIV on children are heightened in endemic regions, including South Africa, where the antenatal HIV prevalence is as high as 40%, and approximately half of all households include an adult on HIV treatment (Bor et al., 2011). Children are exposed to the effects of HIV at a family and community-level from an early age (Rochat et al., 2011). HIV-infected parents face challenges adjusting to parenting with HIV, including preparing their children for periods of illness and ultimately their possible death, both of which have negative psychological impacts for children (Sherr et al., 2014).

Young children (4–6 years) are able to develop an understanding of death using a 'naïve theory of biology' whereby death is understood as having a biological cause (Vlok and de Witt, 2012). During childhood, these naive theories develop, leading to a mature understanding of death that incorporates mastery of several concepts including: inevitability (that living things must die eventually); universality (that inevitability applies to all living things); irreversibility (recognition that the dead cannot return); cessation (that death is characterised by bodily processes ceasing to function); and causation (that death is caused by breakdown in bodily function) (Slaughter, 2005). While traditional psychoanalytic and child developmental theories (particularly Piagetian) suggest that mastery of a mature concept of death emerges in later childhood (9–11 years), more recent intuitive theories argue that children's experience (Hunter and Smith, 2008) and exposure to biological information frame the timing and order in which children master concepts of death (Slaughter and Griffiths, 2007). Providing children with developmentally appropriate information mitigates some of the effects of parental illness and death on the child (Dunning, 2006).

In high-income settings, researchers have shown that primary-school-aged children have few preconceived ideas about the meaning of HIV (Kennedy et al., 2010) and a limited developmental capacity to understand HIV and its potential to cause parental death (Murphy et al., 2006). However, this may not be generalizable to HIV-endemic low-income settings (Rochat et al., 2014). South African research has shown that children have at least a naïve understanding of human disease processes, and in the context of high exposure to death assimilate experience and understanding of external and internal causes of death (Vlok and de Witt, 2012). It is also clear that children's understanding of death is developmentally framed (Christ and Christ, 2006) but strongly influenced by previous exposures (Hunter and Smith, 2008).

In epidemic regions, where approximately a third of children live with an HIV-infected parent, most frequently a mother (Short and Goldberg, 2015) parental support to deal with parent-child communication about HIV and death is an important public health priority. Maternal HIV disclosure has generally been found to be beneficial for children, parents and families (Qiao et al., 2013) and became a World Health Organization recommendation in 2012 (WHO, 2011). However, there is a dearth of interventions to support parents (Kennedy et al., 2015), in particular those with younger children, with this challenging task.

The Amagugu disclosure intervention (Rochat et al., 2013) addressed these parental needs. The conceptual framework of the intervention is described in open access format elsewhere (Rochat et al., 2016) and includes a focus on increasing parent-child communication about HIV (generally, and through parental HIV disclosure) and assisting mothers to prepare for periods of illness. Mothers were encouraged to make either full (using the words 'HIV') or partial (using the word 'virus') disclosures (Qiao et al., 2013). The training addressed maternal preparation for children's emotional reactions and questions following disclosure, including questions about parental death (see supplementary material).

The intervention led to high rates of disclosure (Rochat et al., 2014), including full disclosure (61%). Maternal reports of children's questions post-disclosure illustrated that children had some understanding of HIV illness, transmission and treatment, and that disclosure raised discussion about the possibility of maternal illness and death amongst some children. This data set includes information on mothers' experiences of disclosing, and maternal reports of parent-child communication about HIV post-disclosure. Apart from data published from Amagugu, little is understood about this age group of HIV-exposed children and their understanding about parental HIV in high prevalence regions (Krauss et al., 2013).

The primary aim of this research is to investigate the content of primary school-aged children's death-related questions post maternal HIV disclosure. Secondary aims investigate maternal and child characteristics associated with children asking death-related questions and potential short term consequences of death-related discussions on children's mental health.

2. Methods

2.1. Setting

The research was conducted at the Africa Health Research Institute (AHRI) previously known as the Africa Centre for Population Health, or Africa Centre) in South Africa (2010–2012). The area is mostly rural, has a high HIV prevalence and incidence (Zaidi et al., 2013) and a successful HIV Treatment and Prevention programme, with provision of free drugs and clinical care since 2004 (Houlihan et al., 2011).

2.2. Design

Amagugu was found to be culturally acceptable and feasible when initially tested in a small pilot study (Rochat et al., 2013). 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 randomised controlled trial. The design followed the guidelines for complex interventions (Craig et al., 2008) using validated measures, including multiple data collection points, and collecting qualitative data to inform the development of a randomised controlled trial protocol (NCT01922882).

2.3. Sample

Amagugu re-enrolled HIV-infected mothers with HIV-uninfected children aged 6–10 years who had been part of a large infant feeding study (Vertical Transmission Study -VTS) previously conducted at the Africa Centre, 2001–2006 (Bland et al., 2010). We approached mothers who at the end of VTS were known to be HIV-infected with an HIV-uninfected child (Fig. 1). VTS mothers had tested for HIV during pregnancy, received antenatal and postnatal counselling, were assessed at two years postnatally, including re-testing for HIV and consenting to be re-contacted for future studies. In this Amagugu study the VTS child was purposely selected as the participating child with whom the mother would undertake the disclosure intervention, given their appropriate age, and known HIV status (HIV-uninfected and aged 6–10 years at enrolment). Additional inclusion criteria required that mother and child were in reasonable physical and mental health; mother was living in the study area with her child, and, if migrant, resided with the child for ≥ 2 nights per week, to ensure support during the disclosure period.

Of an available pool of 525 mothers 136 (26%) were ineligible

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