

HIV disclosure and discussions about grief with Shona children: A comparison between health care workers and community members in Eastern Zimbabwe

Anniek J. De Baets^{a,*}, Sibongile Sifovo^b, Ross Parsons^c,
Isidore E. Pazvakavambwa^d

^aFSP/ISPED Zimbabwe, Université Victor Segalen, Bordeaux, France

^bDistrict Health Team, Chimanimani, Zimbabwe

^cDepartment of Anthropology, Johns Hopkins University, Baltimore, MD, USA

^dDepartment of Pediatrics & Child Health, College of Health Sciences, Parirenyatwa Hospital, Harare, Zimbabwe

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Abstract

Research in HIV-related counseling for African children has concentrated on urban tertiary hospitals, but most children have their first health care encounter at a rural primary health care center. This study investigated perceptions about the acceptability of disclosing the parents' or child's HIV status to a child and talking about grief with children, as well as the preferred time, type and setting for HIV disclosure. An anonymous survey was taken from 64 primary health care workers and 131 community members from rural Eastern Zimbabwe. The results expressed a high need and desire for such communications and should be interpreted against a background of high perceived confidence to talk about grief with adults and a high degree of familiarity with child bereavement and foster care. The participants preferred that partial disclosure occurs from the age of 10.8 (± 4.2) years and full disclosure from the age of 14.4 (± 4.5) years. Compared to community members, health care workers were significantly more open to full disclosure and disclosure at a younger age but were slightly less open to discussing grief. The different preferred combinations of persons to initiate such communications included a health care worker in up to 56% of the responses and a family member in up to 52%. The most commonly preferred family members were father's sister (up to 37%) and grandmother (up to 40%) rather than the partner (up to 15%). Southern African family dynamics may hinder a mother initiating HIV disclosure and discussions about grief, even though she is traditionally present during HIV diagnosis, counseling and health education. A more culturally adapted approach than the standard Western 'couple approach' may thus be required. Consequently, counseling training models may need to be adapted. Further research into empowering mothers to involve significant members from the extended family may be highly beneficial.

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*Corresponding author at. 12 Shelley Avenue, Fairbridge Park, Mutare, Zimbabwe. Tel.: +263 20 60716.

E-mail addresses: anisah2@attglobal.net (A.J. De Baets), rossprsns@yahoo.co.uk (R. Parsons), ipazva@zim.co.zw (I.E. Pazvakavambwa).

Introduction

Over the past decades courses in voluntary counseling and testing for health care workers from resource-limited settings paid little attention to HIV disclosure to HIV-infected children. Limited access to pediatric HIV/AIDS treatment resulted in most HIV-infected children dying before their fifth birthday. Furthermore, delayed HIV diagnosis in children often resulted in discussions about death and grief being more appropriate than HIV disclosure (Spira et al., 1999; Taha et al., 2000; Wilfert et al., 1999; Zijenah et al., 1998). Recently, more attention has been paid to pediatric HIV testing and treatment in resource-limited settings (De Cock, Bunell, & Mermin, 2006; Gilks et al., 2006; Michaels, Eley, Ndhlovu, & Rutenberg, 2006; UNAIDS, 2006). Due to the high cumulative mortality rates in kin and community networks, discussions about grief and death remain associated with HIV disclosure. Many caregivers still fear that an HIV-infected child may die ‘any moment’ after the diagnosis has been communicated (Brouwer, Lok, Wolfers, & Sebagalls, 2000; Foster, 2006; Ledlie, 2001; Wood, Chase, & Aggleton, 2006).

Currently used HIV counseling strategies for children are primarily derived from Western psychological models and experiences. It is unclear how far these models are applicable and acceptable within an African culture (Abrams, El-Sadr, & Rabkin, 2005; Friedman, Kippax, Phaswana-Mafuya, Rossi & Newman, 2006; Funck-Brentano et al., 2006; Lee & Rotheram-Borus, 2002; Lester et al., 2002; Raman, 2006; Wilfert et al., 1999). To date, research in HIV counseling with African children has been scarce and has been undertaken mainly in tertiary health care settings (Akpede, Lawal, & Momoh, 2002; Kouyoumdjian, Meyers, & Mtshizana, 2006; Myer, Moodley, Hendricks, & Cotton, 2006; Naeem-Sheik & Gray, 2005; Peltzer & Promtussananon, 2003). Wood et al. (2006) reported on how Zimbabwean children experienced secrecy around HIV in the family. This study aimed at exploring possible explanations for why such discussions may not have taken place by examining adults’ perceived need and acceptance for such discussions with children and their perceptions about the preferred time, setting and type of HIV disclosure to children of different age-groups. Since most African children still reside in rural settings (despite rapid urbanization across the continent) and have their first health care encounter at a

primary health care center, it is important to explore the opinions of community members and primary health care workers from a rural area and to investigate possible differences in opinion between these two groups (Michaels et al., 2006).

This article reports on the perspectives about disclosing the parent’s HIV status to children, disclosing the child’s HIV status to HIV-infected children and having discussions about grief and death with children, as expressed through the responses to an anonymous survey among health care workers and community members from rural Mutare and Chimanimani—two neighboring districts in Eastern Zimbabwe.

Method

Preliminary research for the survey design was initiated after a local psychotherapist (one of the authors of this paper, RP) who runs a therapeutic support group for nine Zimbabwean HIV-infected children from age 12 to 16 years (four girls and five boys), discussed children’s negative experiences due to delayed or non-disclosure of HIV status and lack of communication around issues and experiences of grief. Based on these children’s experiences (Parsons, 2007), a survey was developed to explore possible explanations for the absence of such communication between adults and children in relation to HIV disclosure, death and grief. This was used for nine pregnant mothers and 13 primary health care workers from Chimanimani. Results from these completed surveys and further discussions with health care workers and traditional chiefs from Chimanimani suggested a high acceptability and perceived need for HIV disclosure to children and pointed towards possible gender issues and age-categories for partial and full disclosure (5–10 versus 11–16 years, respectively). We decided to define biological children as ‘children of your own’ and foster children as ‘children you look after, besides your own’. Full disclosure was defined as ‘to have all information’, partial disclosure as ‘being told that there is a disease, but not specified that it is HIV’ and no disclosure as ‘being told nothing’. The questions in this survey and their underlying assumptions were also discussed in depth with the HIV-infected children from the therapeutic group as a form of piloting. The children articulated that more attention be paid to talking about grief and the children’s presence at their parent’s funeral. The children were worried that the girls would be

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