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Changing methods of disclosure. Literature review of disclosure to children with terminal illnesses, including HIV

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Abstract

More than 30 years after the first discovery of the deadly HIV virus, and in the wake of increased knowledge of transmission, treatment and behavioral intervention development, parents are still faced with the difficult task of whether, when and how to inform their child about her or his HIV status. Except for some general ethical considerations, there are no national or international guidelines available for handling HIV status disclosure to a child by parents and health professionals. Most studies on disclosure address the problem of stigma and the barriers to disclosure of HIV-positive status by adults to their sexual partners, caretakers, families and communities, but very few studies focus on disclosure to HIV-positive children. The majority of the studies that address disclosure to children limit themselves to stipulating reasons for barriers to such disclosure instead of the skills and knowledge necessary for effective disclosure to a child. Increasing availability of therapy for HIV across the world presses the issue of disclosure to the child. Even so, disclosure for children who are HIV-positive due to vertical transmission continues to be very difficult. There is a lack of interventions that consider guidelines for healthcare professionals, parents or persons involved with taking care of HIV-positive children. These interventions should be designed in an understanding manner towards the culture where they might be implemented and be as appropriate in the view of integrating different family structures and the child's development.

Keywords

HIV vertical transmission; disclosure; child; parent; stigma

Introduction

It is estimated worldwide that 2.1 million children younger than 15 years of age are living with HIV. Of these 1.8 million children are living in Sub-Saharan Africa. The number of newly infected children worldwide is estimated to be 430 000, with an estimated number of 390 000 children living in the Sub-Saharan African countries. Over 7400 new HIV infections arose on a day in 2008. More than 97% were in low- and middle-income countries and about 1200 cases of infections were in children under 15 years of age. Approximately 6200 were in adults aged 15 years and older, of whom almost 48% were women and about 40% were young people aged 15–24 years of age (UNAIDS 2009).

South Africa is experiencing one of the largest HIV epidemics in the world. In 2006 about 29.1% of pregnant women attending government antenatal clinics were HIV-positive (National Department of Health, South Africa 2008). Vertical transmission has resulted in a large burden of pediatric HIV disease and the reversal of gains achieved in reducing child mortality (Horwood *et al*. 2010). In South Africa, HIV causes over 40% of child deaths (Bradshaw *et al*., 2003). HIV-related illness and deaths have had a devastating effect on households and communities (Hosegood *et al.* 2007). Despite the introduction of interventions to prevent mother to child transmission of HIV (PMTCT), high vertical transmission rates have been reported (Rollins *et al.* 2007). Although anti-retroviral treatment is now available, only 61% of the estimated 94 000 children in need have received treatment (UNICEF 2008, Orne-Gliemann *et al.* 2008).

Methodology

This review paper focuses on the published literature concerning the problematic of disclosure to HIV-positive children. I searched for the keywords ‘‘HIV’’, ‘‘positive’’, ‘‘vertical transmission’’, ‘‘disclosure’’ and ‘‘children’’, using Pub-Med and the Gateway Library from 1970 to 2010. I compared the results between first- and third-world countries with the main focus on Sub-Saharan Africa.

Historical overview

Since the beginning of the 1970s there have been some positive changes in regards to disclosure towards the terminally sick child (Bluebond-Langner 1978, Instone 2000). Before the 1970s it was believed that children would not understand the meaning of a serious illness and death, because of their young age (Spinetta 1980, Claflin and Barbarin 1991), and in most instances they were not talked to directly. It was believed the child needed to be protected against any harmful information. Today it is widely accepted that disclosing to the child as early as possible is better for the child’s development and increases survival rates and cooperation from children (Gaylin and Macklin 1982, Waechter 1973). Before the 1980s the main subject of disclosure to children was cancer, which raises different questions from the diagnosis of HIV (Spinetta and Maloney 1975, 1978, Nagler *et al.* 1995, Schulte 2002). HIV affects all age groups, from infants to old people (Bibace and Walsh 1980, Turner *et al.* 1996, UNAIDS 2009). Following the introduction of anti-viral therapy in the early 1990s, people are surviving longer and children who are born HIV-positive can, taking into consideration the availability of treatment and medial adherence, lead a successful life (Domek 2010, Bachanas *et al.* 2001, Battles and Wiener 2002). As treatment expands to HIV-infected children, health professionals and parents, in most cases the HIV-positive mother or the caregivers of the children, are increasingly faced with the task of disclosing to the child (Wiener *et al.* 1998).

HIV-infected children under medical care are seldom informed of their HIV-status, despite some evidence from industrialized countries indicating that disclosure might have positive psychosocial and clinical outcomes (Bachanas *et al.* 2001, Wiener *et al.* 1998). Studies conducted in industrialized nations indicate that the proportion of HIV-infected children who have not had their HIV status disclosed ranges in the US from 25 to 45% (Cohen *et al.* 1997, Mellins *et al.* 2002, Nehring *et al.* 2000, Wiener *et al.* 1998), is as high as 75–82% in Europe (Funck-Brentano *et al.* 1997, Lwin and Melvin 2001, Thorne *et al.* 2000, Nöstlinger and Colebunders 2006) and is 29% in Uganda (Bikaako-Kajura *et al.*, 2006). In the industrialized countries disclosure is influenced by the age of the child, its cognitive development, perceived right to know (Lester *et al.* 2002a, 2002b, Nehring *et al.* 2000), deteriorating health status or questioning by the child. In the developing countries disclosure is more often determined by concerns about adherence to treatment, the level of cognitive development and age. In general, disclosure across cultures seems to be determined by the age of the child and the desire to protect the child against harmful information.

Ethical considerations

Because there are as yet no clear guidelines on how to discuss or disclose HIV status with an infected child, the consequences of full disclosure to the child have not clearly been examined. Studies differ as to whether a higher incidence of psychological and behavioral problems occurs among children who have not been told about their diagnosis vs. children who have been formally told. There are difficulties around the issue of how to talk to the child and what should be said, in addition to who should talk to the child. The dilemma also occurs if the parent refuses to tell the child that he or she is HIV-positive out of fear of how the child might react or what the child might say, or that the child might talk to others, which might lead to gossip. Another reason is fear of blame, or stigma and isolation. The health professional might respect the parents' wish not to inform the child despite knowing that the child has become sexually active. The ethical responsibility is questionable for either side (Kietzman 2008).

The doctor–patient ratio is much higher in developed countries than in developing countries. Therefore, the issue of disclosure might be handled differently in different parts of the world. In the Western world, with sufficient medical professionals, psychologists and social workers, there is more time to spend with a single patient than in the developing countries, where there is a lack of health professionals. The disclosure process might very often be processed by a specially trained nurse rather than a doctor and is less likely to be accompanied by a psychologist.

Since more children will be born who are HIV-positive, it is crucial that guidelines are developed for concepts on how to disclose, not only for health professionals but also to assist parents and caretakers. This is important because they live with the child and have daily contact with her or him. In countries with less medical resources and fewer health professionals, it might not be practical for medical doctors to take the time needed to appropriately disclose to the child. Guidelines for health professionals and parents on how and when to disclose are urgently needed (Kietzman 2008).

Informed by whom?

One question that seems to play an important role in Western society concerns who should inform the child. Typically clinicians have assumed the responsibility of informing the child about the disease, believing that they have the right to do so because they have the knowledge (Kietzman 2008). This assumption has been questioned in Africa, where most parents and caretakers believe that they are the best person to talk to the child (Wiener 1996, Lester *et al.* 2002a, 2002b, Moodley *et al.* 2006, Lesch *et al.* 2007). In this context, therefore, the parent should be an important target for guidance about the disease, infection, transmission, diagnosis, symptoms and treatment. Without this combination of knowledge and skill, the parent can feel disempowered and refuse to talk to the child while the child might be getting older and engaging in risky sexual activities without knowing the risks. As a consequence, the uninformed child may unknowingly infect others (Kietzman 2008). Interventions in Southern Africa should, therefore, focus on empowering the parents, in addition to health professionals, in order to more effectively affect the behavior of HIV-positive children.

Age of child

At the beginning of the 1990s the question was no longer whether the child should be told, but rather ‘‘how and when should the child be told’’ (Lester *et al.* 2002a, 2002b, Kietzman 2008). Very often parents try to prevent the child from learning the diagnosis of HIV. Most parents delay disclosure until the age of around 10 years and prefer not to use the term HIV or AIDS in the presence of the child. About 50% of parents believe that disclosure should occur before the age of 12 (Blasini *et al.* 2004). The researchers argue that providing such information as early as possible is critical for the development of the child and that requisite programs need to be developed that are age-appropriate for the child.

Reasons and barriers to disclosure

Domek (2010) examines reasons for disclosure and non-disclosure as well as the benefit of both. Domek suggests that it is important to understand the major barriers to disclosure and the fear associated with disclosure in order to develop appropriate guidelines to prepare the HIV-positive child for the future. In this regard it might be useful to have a multi-professional team to assist the caregiver by adapting the disclosure discussion in order to meet the developmental phases of the child.

I found only five publications by authors published in Sub-Saharan Africa studies (Abadía-Barrero and Larusso 2006, Bikaako-Kajura *et al.* 2006, Kouyoumdjian *et al.* 2005, Myer *et al.* 2006, Oberdorfer *et al.*, 2006). They try to better understand the problematic issues around disclosure to an HIV-positive child (Flanagan-Klygis *et al.* 2001).

Most studies do not specify the mode of pediatric HIV acquisition (Vaz *et al.* 2008, Kouyoumdjian *et al.* 2005, Myer *et al.* 2006). In South Africa, one study conducted using semi-structured interviews with 40 health professionals found that 50% had talked to the patients, but only 18% were involved in the disclosure with the child. The health professionals believed that disclosure should start before the children were attending school and that children would be able to understand the meaning of their infection around the age of 10. They felt that the best person to tell the child would be the parent or caretaker, who should be supported by a health professional with biomedical information. They felt that there was a need for emotional support for the parents and their children (Myer *et al.* 2006).

Kouyoumdjian *et al.* (2005) explored in a South African study the reasons for disclosure or non-disclosure among parents or caregivers. Seventeen parents and caregivers participated in focus group discussions. Some of the reasons for non-disclosure were identified, including: fear of stigma, which often leads to discrimination, social rejection and isolation for the child; fear of being judged by the child; not having enough information to explain the diagnosis or answer questions; the perception that the child is too young to understand and might tell others; and disclosure being seen as an emotional and/or psychological challenge for the parent or the caregiver.

In Congo, Vaz *et al.* (2008), conducted semi-structured interviews with 19 youth and 21 caregivers. The youth had been informed about their status and the caregivers had disclosed to their children. The youth were an average of 15 years old at the time of disclosure. They felt that it was best to know their status because they were then able to understand why they needed to take medication. For most of them it was necessary to lead a healthy and better life. It was felt that there was a need to assist the parent and the child to understand the disease better to be able to protect themselves and others and to stay healthy. The researchers suggested that programs needed to be developed for the population and should address the psychosocial needs of both the children and the caregivers.

Vaz *et al.* (2010) report in another study the results of interviews with eight caregiver–child dyads in Kinshasa, Congo. All of the children had previously been informed about their status and they ranged in ages between 8 and 17 years. Their caregivers had informed all but one child. From the viewpoint of the children, they were never talked to directly by their health professional, only by their caregivers. The children reported that in most cases they had been told that they suffered from malaria, rather than HIV. The actual disclosure seemed to have happened at a one time rather than over time and appropriate to the age of the child. The children were left alone with their fear and not informed about the disease and the meaning of adherence to treatment (Vaz *et al.* 2010).

Stigma

One of the many reasons why disclosure is such a problem in African society is stigma. Stigma is associated with risky behavior having led to infection, which is considered avoidable (Schulte 2002, Maman *et al.* 2009). Unfortunately this is linked to behaviors such as drug use, promiscuity, homosexuality and transactional sex (Simbayi *et al.* 2007). The fear of stigma is very real in African society since it influences people's behavior towards others, including gossiping and attaching negative terms to the person (Sherman *et al.* 2000, Uys *et al.* 2005).

One of the barriers to informing the child that it is HIV-positive is the fear that the child might tell others such as friends, neighbors or people at the school. This would most likely result in stigma for the family or caregiver. This is especially the case when the parent is HIV-positive, and also depends on the stage of the disease of the parent, which determines their ability to talk to the child (Gaylin and Macklin 1982, Wiener *et al.* 1998, Gerson *et al.* 2001, Visser *et al.* 2008, Horwood *et al.* 2010).

Most of the time the health professionals and parents prefer to prevent any direct conversation about the disease with the child (Vaz *et al.* 2010). The parents may fear that the child might conclude that he or she had done something wrong or that it must be the fault of the parent that the child is HIV-positive. HIV-positive mothers often feel guilty that they did not protect the child against infection. Moodley *et al.* (2006) comes to the conclusion that guidelines are needed for healthcare professionals and parents to assist the parents and guide the children.

Corneli *et al.* (2009) conducted a study in Congo; they interviewed 19 youth, 36 parents and caregivers and 17 health professionals about the role of disclosure. All participants knew their status, and they believed that most youth wanted to be informed about their status to protect themselves and not to transmit the illness to others. They also felt that it made it easier for them to adhere to medication, knowing and understanding the disease. The parents felt that the child had the right to know. In this group, the age of the usual disclosure was between 11 and 15 years. They thought that more information needed to be carefully designed to help children learn their status. The greatest fear was that the child would respond with depression, sadness, worry and fear of death.

Nam*et al.* (2009) interviewed 32 people, of whom 21 were parents, in Botswana, aged around 37 years and their children, aged 5–18 (those aged <5 years were not included) about their reasons for disclosure and non-disclosure. The main reason for the parent to disclose was their own HIV-positive status and when they became sick. The reaction of the children was generally supportive. The reason for non-disclosure was the age of the child, the fear that it would be too painful and the fear of stigma. Generally, sexual health would not be discussed with the parent as it was seen as inappropriate. The suggestion was made that intervention was needed to assist parents and that these interventions needed to be culturally appropriate. No intervention or other developments were suggested.

Campbell *et al.* (2005) conducted a case study in South Africa; they interviewed 44 people and additionally held focus group sessions. They also used diaries. The main problem mentioned with regard to disclosure was the fear of stigma: this is connected with sex, sin and immorality. Some mothers said: ‘‘I have an evil child in the house’’. Sick family members would hide. The main problem was still that people died from anything else but

AIDS. They understood that the main problem lay in intergenerational communication. The solution they saw was further education and communication within the community. No concept was offered.

Moodley *et al.* (2006) conducted semi-structured interviews in South Africa with 174 parents; the mean age of the participants was 33 (17–73), 91% were female and 176 were children aged about 11. The parents believed that the best age to disclose would be around 12 years of age. The parents believed strongly that the child has the ‘‘right to know’’. Some 83% of the participants believed that the parent or caregiver is the best person to disclose, with only 16% feeling that the healthcare provider should tell the child. Generally they would have liked to see doctors being involved in the process of disclosure, but understood that the lack of time did not allow this. There was a general fear that the child would discuss the infection with people outside the family. No program was developed or suggested.

Lesch *et al.* (2007) examined the South African literature, which focused on pediatric disclosure by health professionals vs. parents. The health professionals supported disclosure over several steps. They saw it as unethical when non-disclosure is chosen. Conversely, most parents wanted to protect their child against painful information and often supported partial disclosure. The reason for non-disclosure was generally given as fear of stigma and accidental disclosure.

Intervention studies

There is a dearth of research describing the development and evaluation of interventions to facilitate disclosure. The only published disclosure model we found was by Blasini *et al.* (2004). They evaluated a disclosure model for pediatric patients living with HIV in Puerto Rico. In this model 16 health professionals, 39 parents and caregivers and 40 children participated. The group of researchers, a multidisciplinary scientific team, developed first semi-structured interviews and from these results designed an intervention, which was led with structured interviews.

With these results they developed an intervention to address many of the barriers to open communication about pediatric HIV. Their five-step intervention targeting providers, caregivers, and HIV-positive children involves:

1. training sessions for health professionals in developmentally appropriate disclosure;
2. caregiver educational sessions and peer support groups;
3. child assessment sessions throughout the process;
4. combined family and staff disclosure sessions; and
5. post-disclosure family groups for education and support.

The researchers took into consideration the following important issues in their intervention development:

1. age and development of the child;
2. cultural factors that influence communication as well as concepts of illness and death;
3. family variables;
4. quantity and quality of social support;
5. mental health; and

6. a child’s neurological and cognitive functioning.

The investigators reported that their intervention model promotes healthy psychological adjustment and better adherence in children. Six months follow-up, post-disclosure, 70% of the participating youths endorsed feeling ‘‘normal’’ and parents and caregivers reported that approximately 58% had improved adherence. Although the majority of youths (85%) and caregivers (97%) thought the disclosure was a positive event, and many youth felt more supported by parents (58%), grand-parents (48%), clinic staff (48%) and others as a result of the intervention, there was not a comparison group with which to measure these results.

Discussion

In summarizing the review of the literature one can conclude that most studies are reports on what has been done. These are mainly focus group sessions and semi-structured interviews. No intervention concept has been developed on how to disclose to a child. In the industrialized world, the impression is that the clinicians have the best answer to the problem and should be the persons to talk to the child, because they have the best knowledge about the clinical development of the disease. In African society the parent or the caretaker is seen as the best person to tell the child. The parent might ask a health professional for assistance with the disclosure, but the first person should always be the parent. Guidelines should be developed for disclosure for health professionals, parents and caregivers. Studies have shown that children who know their status develop with fewer problems and have a better understanding of why they have to take medicine. Adherence is much higher among these children (Wiener *et al.* 1998). Many parents also argue that the child has a right to know and needs to be encouraged to lead a normal life, and to be able to protect him- or herself in the future (Corneli *et al.* 2009). An intervention needs to focus on the benefit and the welfare of the child and the goal needs to be to have an understanding of what is best for the child. Programs need to consider the cultural circumstances, and the abilities and developmental stages of the child and the parent.

Perhaps the best question to guide those interested in developing the guidelines that we are here proposing is: ‘‘How can we learn to see through the eyes of the child? How can we learn how children feel and think?’’ Suggestions for disclosure for the child could be developing guidelines for health professionals to assist parents in the steps to disclose to the child. This cannot be a single step and needs to be age-appropriate, considering the development of the child and the skill level of the parents and caregivers. On the other hand the child should be part of the development since it is the child we have to lead into a positive future.

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