

Naming HIV to children: it's time to talk

Katie Rowson

Senior Lecturer in Children's Nursing University of Central Lancashire and CHIVA Health Lead

Introduction

This article is a review of the literature, a presentation of a UK audit, and future proposals.

Informing a child, they are HIV positive remains a challenge for the family, carers and healthcare professionals. The appropriate time to talk to children about their HIV status has changed along with the timeline of medication development. Today, it is recognised that children should be given age-appropriate information from a young age [1].

There are many reasons why children are not told their HIV diagnosis at an earlier age; this is not comparable to, or reflective of, other chronic health conditions. Despite medical advances, psychosocial influences present additional challenges that are yet to be addressed. Stigma and discrimination play a large role in talking about HIV in society. Sharing, or not sharing, an HIV diagnosis can cause social isolation, victimisation and prejudice at a life-changing level [2]. When a child is HIV positive, HIV is often already a family health issue affecting at least one other person within the family unit [3]. Children can relate HIV to life experiences of ill health or bereavement, which makes learning about their diagnosis more complex.

Informing a child, they are HIV positive can instil the caregiver with fear and guilt in relation to transmission [4]. Parents and carers can add a burden of secrecy, due to fear of onward disclosure [5] leading to self-stigma. However, it is evident in practice that talking to a child about their HIV diagnosis can help alleviate the worry and anxiety related to unanswered questions, thus, empowering the child to understand and manage their health more effectively. Trust and support are essential in this process.

It is acknowledged that there are individual situations, such as cognitive impairment, developmental delay and complex social issues that may play a part in the plan or impact of telling a child their diagnosis. Individual needs should always be considered and necessary adjustments made.

The views of young people should be at the forefront of our practice. All children have the right to information and resources that promote their physical, social, spiritual and mental health [6]; this must include empowering them with knowledge and information about their health and supporting them to live well with HIV. Knowledge and understanding of HIV status for children has been explored as a children's-rights

issue. Talking to children about HIV is markedly different to talking about other chronic health conditions of childhood [7]. This leads us to question whether some of these practices support ongoing stigma around HIV.

Literature review

A literature review was conducted to identify existing knowledge and reported experiences of the impact of naming HIV (disclosure of diagnosis) to perinatally infected HIV-positive children and young people. Key search terms included: children, disclosure or naming, and HIV. Disclosure, now recognised as a negatively associated word, has been replaced with 'naming' in practice [8], however, it is unlikely that this would yet be evident in the literature. A CINAHL database search resulted in 67 articles whilst MEDLINE identified 40 articles. Similarity was checked and 14 articles were removed, resulting in 93 remaining for review. Out of these, 25 articles were deemed to have relevance. The main reason that articles were excluded was that the primary purpose and reporting in the articles focused on parental disclosure of their own diagnosis to their child. Additional relevant resources, highlighted in practice, were also reviewed. Most literature reports were based on findings from resource-limited countries offering an international perspective, however, relevance to the UK must be considered.

Barriers to naming

The majority of children living with HIV acquired the virus perinatally [9], which induces guilt, anxiety and fear of blame, this consequently impacts negatively on parental agreement to naming [5,10–13]. The importance of understanding, empathy, parental support and guidance is crucial to establish a partnership between the caregivers, child, and healthcare team.

Arguably, stigma plays the greatest influence on preventing children from learning their diagnosis. Fear related to the impact of stigma is the overwhelming reason for parents or caregivers to resist or refuse naming HIV to their child [1,5,10,11,13–20]. Some parents or caregivers report that the child is too young to become aware of their diagnosis [4,5,11], which again links directly to the impact of stigma and perceived emotional burden on the child. Studies that highlight stigma as a key factor for preventing disclosure date from 1999 to 2014, raising significant concern for progress in HIV awareness and education over a fifteen-year time frame. A cross-sectional study

in Kenya concluded that parents are more likely than the child to report that their child had experienced HIV-related stigma [21]. This highlights an exacerbation of fear in the caregiver, which turns in to a protective mechanism.

Other factors that may influence disclosure include family bereavement [10,13,17]. When HIV-related death has been experienced within a family or community, it is likely that fear could be exaggerated or in some circumstances stigma could be strengthened, along with misunderstanding of the effectiveness of treatment, if treatment is accessible.

Advantages to naming

A number of positive themes were identified in the literature that support the process of disclosure to children and identify the benefits of this process due to improved adherence to anti-retroviral treatment, improved self-esteem and better engagement with health services, thus, empowering children and young people to better manage their health.

A mixed-method review using a survey and semi-structured interviews to observe the personal experiences of parents and children looked retrospectively at the process of disclosure [22]. The sample size of 54 children and 51 adults appears reasonable when considering cohort sizes. Trust was an important factor identified from both parents and children and although the answers were influenced by gender, parenting styles and coping strategies, fear remained an issue. Different paths of disclosure were recognised but despite variety in the process, most participants felt that disclosure had been appropriate.

Adherence to treatment is crucial for long-term survival [24]. Evidence showing the need for improved adherence to treatment supports the need for diagnosis disclosure to children. If a child does not feel unwell or understand why they are taking medication it is difficult to expect ongoing adherence. A number of studies report improved adherence to treatment following disclosure or in those who are aware of their diagnosis [1,5,16,17,19,20,23–26]. A qualitative study interviewed 42 children and 42 caregivers in a comprehensive clinic in Uganda; disclosure was strongly associated with better adherence to treatment [23]. Caregivers and children, not aware of their diagnosis, reported bribery or punishment as methods to attempt to achieve or improve adherence [23]. Despite the date of the study, clear messages are evident: children over the age of 12 who were unaware of their diagnosis were not adhering to treatment, which resulted in treatment failure leading to less treatment options.

Despite the fear of disclosure having a negative emotional impact on the child, quantitative data, which has reviewed emotional and psychological effects of disclosure suggests quality of life is not

affected [28,29], and self-esteem and confidence remain unchanged or improve post disclosure [16,30]. A large assessment of the impact of introducing a disclosure model in Thailand identified positive changes [30]. Cultural influences must be considered, but, with a reliable sample size the positive effects on confidence, improved self-care, better caregiver bonding and improved adherence as well as a reduction in irritability and fear are significant, and strongly support the importance of disclosure. It is reported that younger children had less emotional reaction at disclosure [22], which may support a reduction in fear of emotional impact and less experience of stigma.

Additionally, it is recognised that those who found out at a younger age report higher onward disclosure in interpersonal relationships [25]. It is very difficult if secrecy has been instilled regarding a child's health status to later expect that young person to have the confidence and skills to tell sexual partners their status.

It is clear that a positive collaboration between healthcare professionals and the family is beneficial, if not crucial, in the process of talking to a child about their diagnosis [1,11,13,19,23,31,32]. Maybe one of the most pertinent arguments to move forward with this process and support children and young people to understand and manage their health is the child's right to know [12,17,18,27].

There is an evident demand for further guidelines that are sensitive to the needs of children living with HIV and their families but which support healthcare professionals to lead this process in collaboration with the family where possible [5,33]. The healthcare team must consider the ethical, moral and legal issues impacting on family decisions [34].

Audit

CHIVA recommend that children should be aware of their diagnosis by the age of 9 years [8] with consideration to naming HIV to a child beginning from age 6 years in line with WHO guideline on disclosure [1]. An audit was conducted to identify progress and challenges in naming HIV to children in the UK. Nine centres replied to the audit representing 282 children and young people with almost one-third of children accessing follow-up in the UK [9].

It was reported that naming work is predominantly carried out by specialist nurses or consultants with psychologists and the voluntary sector playing a role in a small number of clinics. A variety of resources were used to aid naming work including the CHIVA website, booklets and videos. Table 1 shows the percentage of children aware of their diagnosis in each age group.

The overwhelming reason for not naming HIV to children in the UK is reported to be parental resistance. The reasons for this are represented in the literature

Table 1: Cohort represented in the audit

Age (years)	Number of children (n)	Aware of diagnosis (%)	Not aware of diagnosis (%)
0–5	11	0	100
6–10	52	61	39
11–16	121	86	14
17–18	98	97	3

review and include fear of blame and fear of onward disclosure, in both of which stigma plays an overriding role. A diagnosis of special educational needs or learning disabilities was also recognised as a barrier; one clinic reported lack of naming tools.

Outcome of Audit

The development of additional resources will begin and be shared with colleagues through the CHIVA website and at national conference to support the notion of naming HIV to children before the age of 9 years. Talking about health must start routinely before this.

Conclusion

Naming HIV to children is an essential part of health and social care that empowers children to manage their health and live well with HIV. The benefits of disclosure identified in the literature include better adherence and better engagement with health services and improvements in family relationships. This presents a strong argument for early naming which is supported by findings from the reviewed studies that suggest no negative effects on quality of life post diagnosis disclosure.

The day must come when children and young people living with HIV are routinely told their diagnosis, are empowered with the knowledge to manage their health and talk about their diagnosis in a supportive society. Until then, healthcare professionals must take the lead in moving naming practice forward and talk to children about their health in collaboration with their caregivers using up-to-date resources. Barriers must be recognised but drivers to overcome these issues to achieve improved adherence, empowerment and emotional well-being are essential.

Acknowledgements

The author wishes to thank the clinics who had responded and participated in the CHIVA naming audit, Amanda Ely (CHIVA Manager) and Rachel Game (Principal Lecturer University of Central Lancashire)

References

1. World Health Organisation. *Guidelines on HIV Disclosure counselling for children up to 12 years of age*, 2011. Geneva:

- WHO. Available at: www.who.int/hiv/pub/hiv_disclosure/en/ (accessed November 2017).
2. Pebody R. HIV, Stigma and Discrimination, 2012. Available at: www.aidsmap.com/stigma (accessed November 2017).
3. Melvin D, Donaghy, S. 2014. Talking to children about their health and HIV diagnosis. CHIVA Guidelines. Available at: www.chiva.org.uk/resources/talking-children-about-hiv/ (accessed November 2017).
4. John-Stewart G, Wariua G, Beima-Sofie KM *et al*. *AIDS Care* 2013; **25**: 1067–1076.
5. Vreeman RC, Gramelspacher AM, Gisore PO *et al*. Disclosure of HIV status to children in resource-limited settings: a systematic review. *J Int AIDS Soc* 2013; **16**: 18466.
6. United Nations General Assembly. UN Convention on the rights of the child, 1989. Available at: www.unicef.org.uk/what-we-do/un-convention-child-rights/ (accessed November 2017).
7. Ely A. Open and Honest Practice When Working With Children, 2012. Available at: www.chiva.org.uk/files/5114/3142/0633/honest-practice.pdf (accessed November 2017).
8. Children's HIV Association. Children's knowledge about their HIV, 2016. Available at: www.chiva.org.uk/files/5614/5261/8934/CHIVA_statement.pdf (accessed on November 2017).
9. Collaborative HIV Paediatric Study. 2016. Summary Data. Available at: www.chipscohort.ac.uk/patients/summary-data/ (accessed November 2017).
10. Instone SL. Perceptions of children with HIV infection when they are not told for so long: Implications for diagnosis disclosure. *J Pediatr Health Care* 2000; **14**: 235–243.
11. Kallem S, Renner L, Ghebremichael M, Paintsil E. Prevalence and pattern of disclosure of HIV status to HIV-infected Children in Ghana. *AIDS Behav* 2011; **15**: 1121–1127.
12. Saunders C. Disclosing HIV Status to HIV positive children before adolescents. *Br J Nurs* 2012; **21**: 663–669.
13. Cantrell K, Patel N, Mandrell B, Grissom S. Pediatric HIV Disclosure: A process-oriented framework. *AIDS Edu Prev* 2013; **25**: 302–314.
14. Ionescu C. Romanian parents keep HIV a secret from infected children. *Lancet* 2006; **367**: 1566.
15. Merzel C, VanDevanter N, and Irvine M. Adherence to antiretroviral therapy among older children and adolescents with HIV: A Quantitative study of psychosocial contexts. *AIDS Patient Care STDs* 2008; **22**: 977–987.
16. Arun S, Singh AK, Lodha R, Kabra SK. Disclosure of the HIV status in Children. *Indian J Pediatr* 2009; **76**: 805–808.
17. Vreeman RC, Nyandiko WM, Ayaya SO *et al*. The perceived impact of disclosure of pediatric HIV status on Pediatric Antiretroviral Therapy adherence, child well-being, and social relationships in a resource-limited setting. *AIDS Patient Care STDs* 2010; **24**: 639–649.
18. Kyaddondo D, Wanyenze RK, Kinsman J, Hardon A. Disclosure of HIV status between parents and children in Uganda in the context of greater access to treatment. *SAHARA J* 2013; **10** (Supple 1): S37–45.
19. Jemmott III JB, Heeren, GA, Sidloyi L *et al*. Caregivers' intentions to disclose HIV Diagnosis to children living with HIV in South Africa: A theory-based approach. *AIDS Behaviour* 2014; **18**: 1027–1036.
20. Punpanich W, Lolekha, R, Chokephaibulkit K *et al*. Factors associated with caretaker's readiness for disclosure of HIV diagnosis to HIV-infected children in Bangkok, Thailand. *Int J STDs AIDS* 2014; **25**: 929–935.
21. Vreeman RC, Scanlon ML, Mwangi A *et al*. A cross-sectional study of disclosure of HIV status to children and adolescents in western Kenya. *PLoS One* 2014; **9**: e86616.
22. Dematteo D, Harrison C, Arneson C *et al*. Disclosing HIV/AIDS to children: the paths families take to truth-telling. *Psychol, Health Med* 2002; **7**: 339–356.
23. Bikaako-Kajura W, Luyirika E, Purcell DW *et al*. Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda. *AIDS Behav* 2006; **10**(Suppl 4): 85–93.
24. Banford A, Lyall H. Paediatric HIV grows up: recent advances in perinatally acquired HIV. *Arch Dis Child* 2014; **100**: 183–188.
25. Wiener LS, Battles HB. Untangling the web: a close look at diagnosis disclosure among HIV-infected adolescents. *J Adolesc Health* 2006; **38**: 307–309.

26. Abebe W, Teferra S. Disclosure of diagnosis by parents and caregivers to children infected with HIV: Prevalence associated factors and perceived barriers in Addis Ababa, Ethiopia. *AIDS Care* 2012; **24**: 1097–1102.
27. Pinzon-Iregui MC, Beck-Sague CM, Malow RM. Disclosure of their HIV Status to infected children: A review of the literature. *J Trop Pediatr* 2013; **59**: 84–89.
28. Butler AM, Williams PL, Howland LC *et al*. Impact of disclosure of HIV infection on health-related quality of life among children and adolescents with HIV infection. *Pediatrics* 2009; **123**: 935–943.
29. Krauss B, Letteney S, de Baets AJ *et al*. Disclosure of HIV status to HIV-positive children 12 and under: A systematic cross-national review of implications for health and well-being. *Vulnerable Children and Youth Studies* 2013; **8**: 99–119.
30. Boon-Yasidhi V, Chokephaibulkit K, McConnell MS *et al*. Development of a diagnosis disclosure model for perinatally HIV-infected children in Thailand. *AIDS Care* 2013; **25**: 756–762.
31. Vaz LME, Eng, E, Maman S *et al*. Telling Children they have HIV: Lessons learned from findings of a Qualitative Study in Sub-Saharan Africa. *AIDS Patient Care STDs* 2010; **24**: 247–256.
32. Santamaria EK, Dolezi C, Marhefka SL *et al*. Psychosocial implications of HIV serostatus disclosure to youth with perinatally acquired HIV. *AIDS Patient Care STDs* 2011; **25**: 257–264.
33. Lowenthal ED, Jibril HB, Sechele ML *et al*. Disclosure of HIV status to HIV-infected children in a large African Treatment Center: lessons learned from Botswana. *Children and Youth Services Review* 2014; **45**: 143–149.
34. Klitzman R, Marhefka S, Mellins C, Wiener L. Ethical issues concerning disclosures of HIV diagnoses to perinatally infected children and adolescents. *J Clin Ethics* 2008; **19**: 31–42.

Correspondence: Katie Rowson
krowson1@uclan.ac.uk