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Talking to children about their HIV diagnosis – a global commentary and debate.

Abstract (100-150 words)

Content / aims

Naming HIV to children remains a challenge. Although studies identify some of the facilitators and barriers to informing children of their HIV diagnosis, further review of practice is required. The aim of this paper is to present a global perspective of naming (disclosure) practices from different settings. A commentary and debate of professionals from four countries is reported with supporting evidence.

Major findings

Healthcare professionals must work in collaboration with families to support early naming of HIV to children or open discussion about HIV in clinics. When naming occurs earlier self-stigma is reduced and children and young people are empowered to adhere to medication, make informed decisions and share their own diagnosis appropriately.

Conclusion

Healthcare professionals play a key role in educating colleagues and the public to reduce stigma and discrimination. Professionals working with children and families living with HIV require support and resources to instil confidence in naming and facilitate naming of HIV status to a child.

Key Words – HIV, Children, Disclosure, Naming, Children's Rights

Key points (major themes of the article 4-6)

1. 1.8 million children (age 0-14 years) were living with HIV in 2019 (UNAIDS, 2020)

2. Access to effective treatment allows HIV to be identified as a chronic health condition and can result in normal life expectancy

3. Naming HIV to children (disclosure) remains a challenge internationally

4. Stigma and discrimination remain significant for children and families living with HIV

5. Health care professionals must challenge and re-educate professionals and the public to address stigma and discrimination

6. Health care professionals play a significant role in normalising HIV

Reflective questions

Do you feel the general public have a good understanding of HIV prevention, transmission and treatment outcomes?

How can you play a role in reducing stigma?

Have you witnessed or been aware of stigma and discrimination related to HIV in clinical settings?

How can you support families living with or affected by HIV in the community setting?

A Case Example

Zanele is 11 years old and in her final year of primary school. Zanele was diagnosed with HIV at 7 years of age and had engaged in care since diagnosis. Following a clinic review it was noted that Zanele was not taking her medication and blood results indicated a high viral load and drug resistance. When adherence was explored Zanele explained she was no longer taking her medication as she “feels fine and doesn’t seem to need it”. Reflection on this case highlights that drug resistance may have been avoided if Zanele understood why she was taking medication.

Background

Global data indicates that 1.8 million children (age 0-14 years) were living with HIV in 2019 (UNAIDS, 2020). UNAIDS (2020) report that 150,000 children were newly infected and 95,000 children living with HIV died in 2019. Most children living with HIV acquire the virus perinatally through mother to infant transmission (Kourtis et al, 2006). Routine testing in pregnancy and advances in treatment and care have resulted in the risk of mother to infant transmission reducing from as high as 40% to less than 0.5% in developed countries (Townsend et al, 2014). Access to effective treatment allows HIV to be managed as a chronic health condition which should result in a normal life expectancy (Pebody, 2018). Despite the decline in new infections and advances in treatment, medical and supportive care of children and young people living with HIV must stay high on our agenda.

Talking to children about their HIV status has changed along the timeline of effective treatment developments; in the pre-treatment era children were rarely told about their HIV status (Weiner, 2007). As treatment availability improved, children were told before adulthood and later during adolescence in recognition of young people becoming sexually active (Weiner et al, 2007). Stigma and discrimination play an unacceptable role in not talking about HIV. Sharing, or not sharing a HIV diagnosis can lead to social isolation and discrimination at a life changing level (Pebody, 2012). When a child is HIV positive, HIV often affects at least one other person within the family unit (Melvin, Donoghy & Conway, 2008), which presents a more complex scenario when telling a child their HIV diagnosis.

This article explores the evidence and presents a commentary based on current naming practice across the globe. Two Paediatric Nurses, a Consultant Paediatrician and a Social Worker who have been actively involved in naming HIV to children across the past two decades, in different international settings, debate current practice. The United Kingdom, Sweden, South Africa and Uzbekistan are the countries represented in the debate.

The role of different health care settings

A comparative discussion identifies significant differences in the four countries discussed, however, Gregory (2016) highlights that most countries face similar challenges: managing the bridge between primary and secondary care, preventing avoidable illness and integrating physical and mental health needs.

Additionally, the United Kingdom (UK) must respond to an aging population, technological advances and an under resourced workforce (Health Systems and Policy Monitor, 2021). The authors agree that these are recognised challenges across the four countries discussed. Understanding of the health care settings across the four countries is warranted so that the impact of this on paediatric HIV care can be considered.

South Africa, with the highest number of children living with HIV, is identified as a developing country (United Nations, 2014). Maphumulo and Bhengu (2019) report that the impact of apartheid continues to play a role in inequality across the healthcare system. A large percentage of the population are dependent on the public health system which is predominantly nurse driven and fair distribution of health professionals remains a challenge (Maphumulo and Bhengu, 2019). Treatment is free at the point of delivery.

Similarly, health care delivery presents challenges in Uzbekistan which became an independent country following the dissolution of the Soviet Union in 1991 (Ahmedov et al, 2014). The World Health Organisation (WHO) present data indicating an increase in HIV cases in Uzbekistan from the year 2000 which continued for at least a decade (Ahmedov et al, 2014). Uzbekistan is part of the WHO driven Universal Health Coverage Partnership scheme that aims to drive the development of primary health care and equitable health care within the country (Ahmedov et al, 2014).

The National Health Service (NHS) in the UK is predominantly funded through taxes and overall budget is a government decision, Health Education England distribute money through clinical commissioning groups (NHS England, 2021). Treatment is free at the point of delivery, much of the population depend on the NHS (NHS England, 2021). It must be considered that money spent on health care in the UK is lower than that in some other European countries (Health Systems and Policy Monitor, 2021). Health care in Sweden is also public and government funded, however, twenty-one county councils are individually responsible for health care in their area therefore approaches may differ depending on the council's political persuasion (Health Systems and Policy Monitor, 2021). Despite the possibility of differing policy this does not affect the national regulation of treatment being free at the point of delivery.

There are similarities as well as significant differences across the countries health care systems. It is imperative that service provision is considered when debating any aspect of care provided for children and young people. The population of children and young people living with HIV and their access to treatment should also be considered.

Demographics

Table 1:

	Sweden	**UK (CHIPS 2021)**	**Uzbekistan (UNAIDS, 2020)**	**South Africa (UNAIDS, 2020)**
Number of children living with HIV	122 (< 18 years)	489 (in paediatric care) (in paediatric care mainly <18 years)	4100 (0-14 years)	310,000 (0-14 years)
Children on treatment	100%	98%	85-90%	63%

Table 1 presents some of the demographical differences of paediatric HIV cohorts across the four countries. The Swedish, Uzbekistan and UK cohorts are significantly smaller than the cohort of children accessing care in South Africa (Swedish National HIV Quality Registry InfCareHIV, 2021, CHIPS, 2021) but the need for specialist care remains pertinent. Furthermore, despite the differences in cohort sizes, the importance of sharing best practice and learning from international cohorts is imperative (Bamford and Lyall, 2014).

Advances in care pose new focuses. The need to name HIV to children growing up with HIV is not new, however, it remains a reported challenge in clinical practice.

Why does naming HIV to children matter?

Children need to be empowered to manage their health and live well with HIV. The needs of children and young people should drive our care delivery. All children have the right to information and resources that promote their physical, social, spiritual and mental health (United Nations General Assembly, 1989) and this must include empowering them to manage their HIV.

Studies summarise that naming HIV to children can improve adherence to their medication (Weiner & Battles, 2006, Vreeman et al, 2013, Arun, Singh, Lodha & Kabra, 2009, Vreeman et al, 2010, Kallem, Renner, Ghebremichael & Painstil, 2011, Abebe & Teferra, 2012, Pinzon-Iregui, Beck-Sague & Malow Cantrell, 2013, Jermott III et al, 2014, Punpanich et al, 2014) which is essential for long-term health and survival. There is no doubt that if a child does not know why they are taking medication it is difficult to expect ongoing adherence. All authors identified this as a practice challenge. It must also be noted that the child may feel physically healthy without medication and is therefore unlikely to identify a need to medicate.

Vreeman et al. (2010) and Boon-yasidhi et al (2013) argue that when children are aware of their HIV status their self-esteem is improved. It is also reported that parents were found to experience reduced depression once a child knows their HIV status (Doad et al. 2019). Rydström et al. (2016) concluded that quality of life in children living with HIV was reported as normal or better than normal in those who knew their diagnosis. A quantitative cohort study in the UK comparing HIV positive and HIV negative affected (sibling or parent living with HIV) young people aged 13-21 years concluded similar anxiety and depression scores in both groups and this was comparable to UK normative data, however, self-esteem scoring was similar in both groups but lower than UK normative data (Le Prevost et al. 2018). The authors highlight that not telling children until adolescence has often resulted in negative psychological consequences. Fear of affecting anxiety, depression or self-esteem in young people should not prevent naming.

Why should we tell children?

Evidence reported earlier in the article discussion supports the need to talk to children about HIV and stop withholding their health information. Collectively the authors agree that there is a need to act against stigma and normalise HIV. It was highlighted in the author debate that advantages of talking openly about HIV could ultimately result in improved community support for people living with HIV, there is a consensus that this would be beneficial to all. The best interests and the rights of the child are of paramount importance and therefore this should drive the need to inform children of their HIV diagnosis.

What prevents telling children their diagnosis?

In the context of Uzbekistan, the author discussed that parent's fears are the biggest obstacle and reported that it is not unusual for parents to request that this needs to wait until adulthood, perhaps even after marriage. In the UK professionals report parental resistance as the most significant barrier to naming HIV to children (Rowson, 2017) and the author representing practice in South Africa concurs that this is a challenge they also experience and this can be complicated by reluctance from health care professionals.. Evidence reports parental requests to delay naming HIV to children until they are older (Weiner, 2007, Kallem, Renner, Ghebremichael & Painstil, 2011, Vreeman et al, 2013). Conversely in the Swedish cohort, the author states that since a drive to talk openly about HIV in paediatric clinic settings there has been little parental resistance or negative feedback. There is also a prerequisite to enable children to learn more about their health in an honest, age-adjusted way.

There is agreement from the authors and in the evidence, that parents report feelings of guilt in relation to transmission of the virus (John-Stewart et al, 2013) and fear blame and onward disclosure by the child which may lead to stigma and discrimination (Vreeman et al, 2013). Empathy from healthcare professionals is essential. However, it is noted that particularly in the context of South Africa, a more complex scenario occurs if the healthcare professional is HIV positive and therefore managing their own emotions based on personal experience. Further complications that may impact on parental willingness should be considered. Experiencing a HIV related death within families or communities is likely to be significant (Instone, 2000, Vreeman et al, 2010, Cantrell et al, 2013). It has also been acknowledged that the caregivers experience of how they found out they were HIV positive may impact on their readiness and willingness to tell their child (Evangeli & Kagee, 2016).

The willingness of professionals must be considered. The authors argue that professionals must be confident in naming HIV to children to ensure that it is clear to caregivers that this is the right thing to do. There is a consensus that confidence is required. All authors agree that there can be concern from professionals about not negatively impacting on therapeutic relationships with the family, however, the Swedish experience is that this risk is overestimated. The author debate also highlighted that some healthcare professionals worry about the reaction of the child and this can delay or prevent naming HIV. History plays a role. Many healthcare professionals have supported children and families living with HIV across a number of decades. The era of no treatment, inadequate treatment and extreme stigma is not that far in the past and at times still significant. This is particularly challenging in some cultures and communities. We learn from practice, it influences future practice, it may exacerbate fear in professionals.

Cultural challenges were highlighted in the author debate and cannot be underestimated. The impact of different health care systems, different community priorities, different normative levels of stigma and different family beliefs must be considered.

Stigma

There is no doubt in the discussions that stigma and the fear of stigmatisation is the dominant factor that prevents naming HIV to children.

Public ignorance and misunderstanding of HIV leads to denigrating perspectives and negative stance which results in people living with HIV continuing to experience stigma and discrimination decades on (UNAIDS, 2020). Consequently, the impact of stigma and maintaining secrecy of their diagnosis is often part of growing up for children living with HIV (Bamford and Lyall, 2014).

Stigma is overwhelmingly highlighted as the reason parents do not want their child to know they are HIV positive (Merzel, VanDevanter & Irvine, 2008, Arun, Singh, Lodha & Kabra, 2009, Vreeman et al, 2013, Kallem, Renner, Ghebremichael & Painstil, 2011, Cantrell, Patel, Mandrell & Grissom, 2013, Kyaddondo, Wanyenze, Kinsman & Hardon, 2013, Jermott III et al, 2014, Punpanich et al, 2014, Evangeli & Kagee, 2016, Doat, Negarandeh and Hasanpour, 2019).

The authors suggest a generational difference in perspectives of parents and that of young people wanting to share their HIV status. A cross-sectional study in Kenya concluded that parents are more likely than the child to report their child had experiences of HIV-related stigma (Vreeman et al, 2014). This highlights an exacerbation of fear in the caregiver and will result in reluctance to name HIV to children and of fear of children sharing their diagnosis.

(insert picture 1)

So what's happening globally?

UK guidelines recommend fully naming HIV to children before the age of nine (CHIVA 2016). Clinical practice was audited in 2017 and a significant number of children over the age of nine were unaware of their HIV status (Rowson, 2017), it is suggested that this is unchanged. Similarly, in South Africa and Uzbekhistan national guidelines state children should be fully aware by 10 years old. This is recognised as full disclosure. The practice in Uzbekistan is to start talking about HIV to children from the age of seven years. The authors highlighted that legal, ethical, and developmental considerations play a role. There is agreement that individual circumstances must be considered. However, after much debate the authors concluded that there is never a right time and due to the highlighted challenges, a reason to delay is almost expected. In Sweden the recommendation is to talk openly about HIV from the first consultation and continue to have a dialogue with the parents about why this is good for the child, this has been a standard of care for twelve years (Erikson et al. 2020). A reflective discussion suggested that within the context of Sweden a number of children who reported that at disclosure they didn't know about their HIV later shared that they had known long before HIV was named. The effect of a hidden secret can result in self stigma and may play a role in young people sharing their diagnosis in the future.

A cross-sectional study conducted in Sweden (Rydström et al. 2016) highlighted that children and young people report some concern around onward disclosure of their

HIV status and therefore supporting children with this is essential. Weiner and Battles (2006) report children who found out about their HIV at a younger age report higher onward sharing of their diagnosis in interpersonal relationships. The authors call attention to the risk of creating self-stigma through not naming HIV to a child. Normalising HIV is key.

“It’s ridiculous”

The author discussion highlighted that we have a responsibility as healthcare professionals to challenge stigma and change perspectives. There is a clear consensus in the debate that healthcare professionals play a crucial role in educating colleagues and the general public. It’s like a circle, healthcare professionals should accept professional responsibility to break this cycle.

Can we stop using the term disclosure and talk about naming? A debate.

It can be argued that disclosure is a term often associated with sharing something negative. When talking about a HIV status naming or sharing would be appropriate terminology. The author reports that in the UK activists and professionals are trying to stop the use of disclosure as a term in the context of sharing a HIV status. Research refers to disclosure, it is a recognised term, and this presents a challenge. The authors agree that this term is outdated, with adequate treatment HIV is a chronic disease and there needs to be a positive shift in care discussions. The author reports that there have been attempts to change this in South Africa but guidelines refer to disclosure. In Uzbekistan, the author stated that disclosure is the recognised terminology used in health and social care settings. This is a challenge that will take time, authors agreed that healthcare professionals should be mindful of the impact of word choices on children and families. Children should be offered age-adapted education to be able to accept and learn to live with a chronic health condition involving complex situations. Children need to be knowledgeable about their HIV diagnosis, treatment, transmission and how to live well with HIV.

When can we talk openly?

It is promoted within the debate that it is time to talk openly about HIV in line with the positively accepted change in practice in Sweden. The author debate suggests professionals need to be brave enough and confidently promote this. It is time to educate and challenge public and professional knowledge, there will be challenges but challenges are created through not talking. It is reported that stigma is a significant challenge in Uzbekistan and this prevents a change in practice. One author reports that we will talk openly when something worse is reported "people started to talk more openly about cancer when HIV emerged".

What next?

The WHO (2011) promote the need for a positive collaboration between health care professionals and the family in the process of talking to a child about their diagnosis. Britto et al (2016) conducted a systematic review which highlights the pivotal role of the health care professional in naming HIV. A study by Vreeman et al (2014) highlighted that although fear to disclose remained, trust between the healthcare professionals and family was an important factor for both parents and children in successfully naming HIV to the children.

It is reported that younger children had less emotional reaction when HIV was named (Dematteo et al, 2002). These findings were also reflected in experiences of the authors involved in naming HIV to children at younger ages.

It is proposed that the possibilities of supporting individual clinics to change practice and then share best practice with others in similar community settings may be the best approach. This can be considered in national teams across the UK, South Africa and Uzbekistan. Equipping health care professionals with education, support and adaptable resources is key.

Conclusion

It is essential that practice experiences are shared, and this commentary has created the opportunity for an international debate summarising practice approaches of telling a child they are HIV positive. It is imperative that children's rights remain at the forefront of clinical practice. This debate has also opened the opportunity of collaborating and sharing resources and experiences on an international platform. Health care professionals play a vital role in reducing stigma and normalising HIV. This may need to involve the role out of up to date information in health care organisations, communities, and the media. Each author will consider culture sensitive approaches to this. It is time to stop stigma and normalise HIV. It is time to talk.

Whilst we hope to achieve open discussion in all settings this is a complex multi-dimensional process. We conclude this article with a call for action and draw attention to the readers role in addressing stigma and normalising HIV.

IMAGE 2

IMAGE 1 and 2 to be added – send as JPEG files (images of young people's art work from CHIVA camp (CHIVA to be acknowledged for images)

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