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It's time to tell: Early naming of HIV to children can break the cycle of intergenerational stigma and reduce self-stigma.

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Abstract

Children living with HIV are not routinely informed of their HIV diagnosis: open communication is not yet standard global practice (Warburton et al, 2022). This article presents data from a qualitative study aimed at establishing an evidence-based approach to telling children they are HIV positive. An arts-based narrative inquiry methodology was used. Sixteen young people and ten parents were recruited via voluntary sector organizations in the United Kingdom and shared their experiences through focus group participation. Participants used arts resources to create something of their choice as a vehicle to share their untold stories. Creative pieces made by participants included masks and boxes illustrating the experiences of stigma and self-stigma and highlighting the need felt by participants to hide HIV. Stigma prevents HIV-related conversations and creates self-stigmatization. Secrecy in family homes exacerbates self-stigma and a cycle of intergenerational stigma, as a new concept, was identified in the narratives. The burden of hiding a health diagnosis is an overwhelmingly negative experience for children and their families. Early naming of HIV and open communication will reduce the weight of self-stigma and intergenerational stigma experienced by children and families. It is time to break the cycle of stigma.

Key Words HIV, Children, Disclosure, Stigma, Good Health and Well Being

Introduction

Global data indicates that 1.4 million children (age 0-14 years) and 1.5 million young people (10-19 years) are living with HIV (World Health Organization (WHO), 2024). In England, 481 children and young people were reported to have accessed pediatric HIV care in 2022/23 (Children's HIV and AIDS Reporting System (CHARS), 2024). Although effective treatment has decreased morbidity and mortality in childhood, the psychosocial implications of stigma and secrecy continue to be dominant factors for children and young people living with HIV (Robinson et al., 2023).

Historically, the act of informing children about their HIV status has been referred to as "disclosure." However, the term "disclosure" often carries connotations of sharing distressing or negative information. In alignment with the People First Charter (Waters, 2022), this article will avoid using the term "disclosure" when referring to conversations about HIV. Instead, *naming HIV* or *talking about HIV* will be used. This choice reflects a commitment to reducing stigma and promoting respectful, person-centred language. Guidelines on the process of talking to children about their HIV diagnosis has changed along the timeline of effective treatment developments (Weiner et al, 2007). International guidelines indicate that children living with HIV should be aware of their diagnosis before 12 years of age (WHO, 2011), while national guidelines indicate that children in the UK should be aware of their diagnosis before nine years of age. However, national data resulting from an audit conducted in 2017 in the UK, which investigated naming HIV to children, illustrated that a significant number of children (39% aged between 6 and 10 years old) accessing HIV care are unaware of their own HIV diagnosis (Rowson, 2017). A number of systematic reviews illustrate the global contravention of the guidelines, reporting that most children living with HIV are unaware of their HIV diagnosis, thus, naming HIV to children remains a limited practice (Belay et al, 2022, Britto et al, 2016, Doat et al, 2019, Krauss et al, 2016, Pinheiro et al, 2020, Pinzon-Iregui et al, 2013, Vreeman et al, 2013) regardless of the guidelines and policies in place. In her literature review, Rowson (2017) highlighted parental resistance, fears of blame and onward sharing of diagnoses as barriers, indicating that stigma plays a key role in delaying HIV naming (Rowson, 2017). Avoiding naming HIV to children has also been observed in other parts of the world, and irrespective of organizational and cultural differences, resistance in naming HIV is apparent. A quantitative national study in Malawi reported that less than 25% of children living with HIV were aware of their HIV diagnosis (Kalembo et al, 2018). Furthermore, Doat et al. (2019) conducted a systematic review on the naming HIV to children in sub-Saharan Africa, reporting that in 39% of the included studies, the child's age influenced whether HIV was named. Notably, one study reported that only 9% of children were aware of their HIV diagnosis. There are structural and contextual contrasts

affecting naming HIV to children either in the UK where clear guidelines are available, or in lower-income countries with differing support systems. While it is important to consider cultural diversity in the international context, similarities are observed in the barriers associated with naming HIV to children across many countries (Warburton et al, 2022).

This article focuses on intergenerational stigma and its impact on naming HIV to children living with HIV. Research spanning across two decades highlights caregivers' fears related to the impact of stigma as the overwhelming main reason caregivers may resist naming HIV to their child (Qur'aniati, et al, 2024, Mphego et al 2023, Evangeli & Kagee, 2016, Madiba et al, 2012, Lonescu, 2006, Boon-Yasidi et al, 2005). A quantitative study in Ghana recruited 180 caregivers and provided further insight into caregiver's fear of a negative response from the child and fear of social isolation (Appiah et al, 2019). HIV stigma drives parental fear and is repeated as an overarching barrier to HIV knowledge for children (Alarcon-Vasquez et al 2021, Baker et al, 2018, Khangale, Raliphasw & Tshililo, 2022, Lencha et al, 2018, Lonesco, 2006, Madiba & Mokwena, 2012, Mphego et al, 2023, Qur'aniati et al, 2024, Wariri et al, 2020, Waugh, 2003). One can see from the data spanning 2003 to 2024 that the impact of HIV stigma in this arena remains. Mphego et al (2023) conducted a qualitative study in South Africa including semi-structured interviews with 22 caregivers highlighting stigma as the dominant barrier to not informing children they are living with HIV. While stigma prevents naming HIV to children, the consequence of not naming HIV to children ignites internalized or self-stigma (discussed below). For example, a qualitative study that heard the experiences of 51 healthcare workers via focus groups concluded that not naming results in internalized stigma in children (Madiba and Diko, 2020), and Midtbo et al's (2012) interviews and focus groups with adolescents and healthcare workers in Tanzania and Botswana reinforced the significance of internalized stigma in young people living with HIV. Kitetele et al (2022) highlighted that there was no negative impact on the child when HIV was named, and reported that mental health improves in children who are aware of their HIV diagnosis. Controversially, a quantitative study that conducted 250 case note reviews and questionnaires reported that there could be an emotional impact but only when children were told later, specifically after the age of 12 years (Garcia-Boyano et al, 2022). A qualitative study recruited 362 children in India and reported that children themselves were not worried, but recognized worry carried by their parents or caregivers (Sanjeeva et al, 2016).

Stigma

Exploring stigma and its associated action requires an understanding of the underlying theory (Birbeck et al, 2019). When an attribute is discredited by society, structural and cultural factors prevent the complete social acceptance of those affected (Goffman, 1973),

illustrating how stigma is socially constructed. An association can be made to labelling theory which suggests that particular labels are given to actors of society who have specific attributes or characteristics (Becker, 1974, Link and Phelan, 2001). Stigma is recognized as a social process in which such attributes or characteristics arrive with a label of inferiority (Link and Phelan, 2001), a process that demonstrates how embedded societal expectations of “normal” are derived by society and can result in categories of acceptable and unacceptable. Stigma grows through social relationships with multiple factors shaping individuals’ beliefs and expectations (Pescosolido, Martin, Lang, and Olafsdottir, 2008), demonstrating the social construction of specific stereotypes. This societal expectation is based on accrued knowledge whether accurate, myth or misconceptions. Phelan, Link and Dovidio (2008) propose that stigma aims to manage “exploitation and domination (keeping people down); norm enforcement (keeping people in), and disease avoidance (keeping people away)” indicating that one must understand this notion when exploring and addressing stigma.

Visibility of a stigma is important and when non-visible attributes that carry stigma are present, this opens a debate of whether to tell or not, to lie or not. Stigma reduces opportunities and leads to insecurity caused by the notion that one can never be sure of the response of others (Goffman, 1973), thereby creating social exclusion. Stigma is a power that drives inequalities (Hatzenbuehler, Phelan and Link, 2013, Taylor, 2020). Stigma must be recognised as a social determinant of health because stigma-driven inequalities have consequential negative impact on health outcomes (Hatzenbuehler, Phelan and Link, 2013). Deacon (2005) discusses HIV related stigma and reports that the findings paint a “social landscape of prejudice” that surrounds people living with HIV as individuals, as a group and with associated others. Health inequalities are exacerbated when stigma relates to a health diagnosis which can have profoundly negative effects.

Social exclusion due to the public understanding of a health-related diagnosis is widely noted (Mason et al, 2001) and is recognized with an HIV diagnosis (Carlisle, 2001). More specifically, it negatively affects physical and mental health in adults living with HIV (Rueda et al, 2016) and causes mental health difficulties and challenges with engagement in care in children and young people who have grown up with HIV (Aurpibul et al, 2021, Rydstrom et al, 2016). HIV stigma is seen in the way people react to HIV which reflects their understanding of HIV (Wallis, 2011). Andersson et al (2020) reported HIV related stigma as a human rights challenge and, it is clear that, HIV related stigma affects the full care cascade including testing, accessing care, adherence to treatment and engagement in care (McHenry et al, 2017). Perger et al (2025) reported stigma as a barrier to care for children and young people, which negatively affects adherence to treatment, engagement and retention in care,

sharing their diagnosis with others and transitioning to adult services. A qualitative study in Zambia confirmed that stigma is an interpersonal barrier for children and adolescents across the HIV care continuum (Mesic et al, 2019).

There is consensus that stigma affects physical and mental well-being (Hartog et al, 2020). To some extent this is also recognized in childhood mental health diagnosis with quantitative evidence noting that stigma creates a barrier to treatment for children and young people with mental health conditions (Pescosolido et al, 2007). Significantly, it has been proposed that stigma increases morbidity and mortality when associated with health conditions (Hatzenbuehler, Phelan and Link, 2013) and this can most certainly be aligned to HIV when the impact on engagement and retention in care has been identified. It should be noted that mental health diagnoses are similarly stigmatised (Pescosolido, Martin, Lang, and Olafsdottir, 2008) and therefore the mental health implications of HIV related stigma create a co-stigmatized scenario. Moreover, it is recognized that for some people living with HIV concurrent characteristics such as sexual orientation and ethnicity, which are also stigmatized, will amplify the impact of stigma (Stagl et al, 2019, Teran et al, 2020). It is clear that, stigma carries power that drives health disparities (Andersson et al, 2020, Cook et al, 2014) and is therefore exacerbating challenges associated with engagement in HIV focused health care.

Earnshaw and Chaudoir (2009) presented an HIV stigma framework that categorises stigma as enacted, anticipated and internalized. A qualitative study conducted in Kenya interpreted adolescent and caregivers' experiences of HIV stigma as perceived, enacted or experienced, internalized or courtesy stigma (assumptions from others) (McHenry et al, 2017, Mesic et al, 2019). Societies' understanding of HIV played a key role in participants' stories (McHenry et al, 2017) with both perceived and internalized stigma resulting from fear, shame and misconceptions. A mixed-method study conducted in Zambia described the role of stigma in interpersonal, intrapersonal and community related barriers that adolescents living with HIV may experience (Mesic et al, 2019). Similarities in assumptions and fear were observed in both papers. Internalized stigma was significant.

Self-stigma

Internalized stigma is described in this paper as self-stigma. When someone has a characteristic or attribute known to be stigmatised by society one can never be sure whether they will experience acceptance or rejection (Goffman, 1973). Furthermore, HIV is not an attribute visible to others and therefore one's presumptions, perhaps driven by previous personal or learnt experience of society's responses to HIV, internally fires self-stigma. Some people experience an internal belief that HIV will not be accepted by others. Internalized

negative feelings associated with HIV are reported to be experienced by caregivers and adolescents living with HIV (McHenry et al, 2017). Self-stigma can have negative consequences on emotional regulation and coping strategies in individuals that internalize stigma associated with a personal attribute (Hatzenbuehler, Phelan and Link, 2013), consequently affecting self-worth and emotional well-being. Self-stigma drives negative expectations and the fear of rejection is seen in the narratives of the participants in this study. Hatzenbuehler, Phelan and Link (2013) propose that negative expectations increase stress, which exacerbates health challenges and consequently increases social isolation. The result is an increase in inequality. A HIV diagnosis directs people to develop personal expectations of how society may treat them, which can lead to decision-making based on these assumptions. Reducing HIV related stigma is essential for promoting equitable health care and supporting global targets to reduce new HIV diagnoses and improve diagnosis and treatment effectiveness (Andersson et al, 2020).

The harmful effects of stigma on people living with HIV and the HIV epidemic have been noted (National AIDS Trust, 2016). UNAIDS (2018) recognizes the necessity to eliminate HIV related stigma as a core component of ending the HIV epidemic by 2030, and specifically proposes that less than 10% of people living with HIV should experience HIV related stigma and discrimination in 2025. However, the 2025 stigma target has not yet been achieved. To achieve this, it is necessary to understand the complexities of HIV related stigma within families, specifically for children and young people, as the next generation grows up with HIV.

The SKETCH Study (**T**he **S**tories we need to **K**now about the **E**xperiences of **T**elling **C**hildren they are living with **H**IV).

This qualitative study enabled parents and children to share their stories so that the experiences of young people and parents who have experienced the process of being told or of their child being told, they are HIV positive, in the UK could be heard. These stories provide new knowledge and an understanding of experiences so that an evidence-based best practice approach to telling children in the UK that they are HIV positive can be established. Careful consideration of the wide range of psychosocial factors reported in the participants' stories informs future delivery of care. This study investigated the significance of stigma in children's and parents' narratives and proposes a direction of change in practice to reduce the identified adverse effects.

The first author has extensive experience in HIV care, whilst the remaining researchers do not. Reflexivity is recognised as essential in qualitative research to reduce unconscious bias (Buetow, 2019), particularly for nurse researchers who must navigate dual roles, with open

dialogue about thoughts and feelings enhancing transparency (Dowling, 2006). Scholars advocate for the integration of professional experience into research (Braun and Clarke, 2022, Coulbourne and Sque, 2004). Reflexivity by critical engagement with one's positionality and its influence on research actions is important (Finlay, 2002) and has been actively managed throughout the study using a reflexive log, supervision and review meetings.

Methods

The SKETCH study utilizes qualitative methodologies to hear the stories of parents whose children have been told about their HIV diagnosis and of children who are aware they are living with HIV. Ethical approval was obtained from the University of Lancashire Ethics Committee (Health No.0286). After providing informed consent, the participants joined one of four focus groups which included arts-based activities, undertaken between 2022 and 2023. Two focus groups were conducted with young people and two were conducted with parents with the recognition that focus groups can provide connection and communities. The duration of each focus group was between 2.5 - 3 hours.

The intertwining of the research paradigms of Critical Realism, Ubuntu and Social Constructionism underpinned this arts-based narrative inquiry. As a methodology, arts-based narrative inquiry provides a systematic approach to support participants in sharing their stories. Participants were invited to utilize a wide variety of art and craft materials to make a creative piece of their choice that told their story about how they learnt of their HIV diagnosis, and for parent participants, how their child learnt of their HIV diagnosis. Posters were displayed around the room for guidance which stated: think about own experience, think about challenges or barriers to naming, think about feelings before and after naming, think about things that helped, think about advantages, think about things that would help others going through the same experience. No guidance on what to create was given. Participants were then invited to describe their creation and use their creative piece to share their stories in a facilitated focus group discussion. The verbal and non-written approaches ensured that the voices of participants were heard. The focus group discussions were audio-recorded and transcribed verbatim by the researcher.

Participant demographics

Participants were recruited via voluntary sector organizations in the United Kingdom. An advertising poster and video promoted recruitment in voluntary sector organizations that specifically support people living with HIV, including advertisement at national events. This resulted in voluntary sampling, recruiting all those who met the criteria, which provided a

diverse participant group. Sixteen young people with a median age of 17 years, were recruited for this study. 75% of young people were female, and 31% were born outside the UK in Cameroon, Germany, Kenya and Nigeria. Participants lived across the UK (Ireland, London, Midlands, North-East, North-West, Scotland, South and South-West). HIV had been named to participants between 8 and 13 years of age. Ten parents were recruited, of whom 80% were female and 80% were born outside the UK, in Angola, Malawi, Nigeria, Uganda and Zimbabwe. Parent participants lived across the UK (London, Midlands, North-East, North-West, Scotland and South). HIV was named to the children of parent participants between 8 and 10 years of age. All participants are living in the UK with HIV and aware of their diagnosis. All participants could speak and understand English.

Data Analysis

Datasets and photographs of the participants' creative pieces were added to NVivo for analysis. Braun and Clarke's six steps of reflexive thematic analysis (2023) were followed. The reflexive thematic analysis approach was selected to ensure that participants' voices remained central in the dataset, with the purpose of identifying meaning in people's stories through patterns and themes. Coding was conducted by a single researcher, with ongoing discussion and review involving the wider research team to ensure rigour, consistency, and shared understanding of emerging themes. Analysis was predominantly inductive, reflecting the aim to identify meaning from participants and not from the researcher or previous research. Data saturation was achieved as identified themes were richly developed and consistently supported across participants' stories. This was monitored through iterative coding and reflexive thematic mapping.

Results

Five themes emerged in both the parents' and young people's datasets. Stigma was a dominant thread in all themes and was an overarching issue. Stigma was anticipated as a barrier at the outset of the study, but intergenerational stigma emerged as an organic finding of this study through inductive analysis of the data as participants consistently described experiences and perceptions that reflected this in all focus groups. Intergenerational stigma was identified as a finding in two themes in young people's stories: "**How do we find out about the secret?" Tell us please** and **"I've made it my life mission not to tell anyone".** Intergenerational stigma was identified as a finding in four themes in parents' stories: **"A horrible dark cloud" arrives with a HIV diagnosis, "That is my burden to carry", "I wish I could have told her earlier" and "The best thing I ever did – naming HIV".** HIV stigma frameworks have identified categories of stigma as enacted, anticipated, internalized or courtesy stigma (Birbeck et al, 2019, Earnshaw and Chaudoir, 2009, McHenry et al, 2017,

Mesic et al, 2019). Whilst these categories are identified, and reflected in the dataset, this article discusses the finding of intergenerational stigma as a new concept.

“**How do we find out about the secret?” Tell us please**

Young people reported that they had learned about their HIV diagnosis between 8 and 13 years of age. Being male or female and being born in or outside the UK did not influence age at naming. Some participants report that they already knew but nobody would tell them, which is representative of perceived and anticipated stigma:

“I kinda already knew a long time ago, I knew I had it but like it never got confirmed but I kinda knew and no one really told me”

This delay in naming exposed participants to negative myths and misconceptions about HIV, which instilled fear and endorsed the negative knowledge and societal views of HIV that can be associated with HIV stigma. One child encapsulated the fear: *“I thought I was gonna die soon”;* whilst another child highlighted fears driven by their own pre-knowledge of HIV: *“I was quite confused and then I started crying, because at this point, I knew what HIV was”.*

Young people report that they want to know about their HIV diagnosis at a young age and the dialogue illustrates their request for open communication about HIV:

“It’s like when you have a baby you teach them the basic things … so when it comes to HIV it should be like a routine … like part of the routine of growing up”

“It needs to be younger cos then you have a lot of time to grow with it”

Some participants attributed the delay in naming HIV to parents’ fears and emotions, and these were recognized as influencing factors. Here we see perceived and anticipated stigma from parents resulting in enacted stigma for children which highlights the complexities of HIV stigma in families. Young people highlighted that they did not want their parents to be fearful of the controllable and uncontrollable factors associated with HIV stigma:

“I feel like a mother should not feel guilty about passing HIV on to their child and it bothers me when they do cos it’s not their fault ..... if you’re feeling guilty that’s gonna make me feel like it’s something even worse than it actually is”

Children are not routinely told about their HIV diagnosis and this presents a rippling effect of challenges that exacerbate the adverse psychosocial factors associated with HIV. The currently uncontrollable factors include the development of HIV myths and misconceptions generated by public stigma whereas the controllable factors of secrecy and hiding instil self-

stigma. Here we see perceived, anticipated and endorsed components of the complex stigma phenomenon.

“I’ve made it my life mission not to tell anyone

Perceived stigma leads to secrecy which supersedes HIV naming for children living with HIV. Prior to HIV being named children have taken regular medication and attended regular health checks without an honest explanation. Young people’s narratives tell us that when HIV is named to children secrecy is instilled and stigma is endorsed.

“It’s like a constant lie that even you have to believe kind a thing, it’s not, yeah it’s a secret but like it’s a secret you never tell”

“I made it sort of like my subconscious life mission to make sure nobody finds out”

Hiding HIV is also a common practice in the family home reinforcing secrecy, which we recognize as negative messaging. Young people report that this instils the belief that HIV is something bad, which illustrates experiences that add to the burden of self-stigma.

“My mum was like close the door, close the door make sure they’re all in their room lock the door I don’t want anyone else to hear this, so I thought it was something bad …. it was that deep that no one could hear it”

“Sometimes I wouldn’t take my meds and um I also had denial because my father would not believe I had it”

For many, the home is a safe place with trusted others; therefore, negative HIV messages in the home are significant and these participants describe the detrimental effects on children and young people.

“A horrible dark cloud” arrives with a HIV diagnosis

Parents’ stories begin at the point of an HIV diagnosis, and, as with young people’s narratives, parents reflect on their pre-knowledge of HIV, which illustrates perceived and endorsed HIV stigma within society. Here we see labelling theory (Becker, 1974, Link and Phelan, 2001) in the context of HIV.

“I see a poster get tested but I think it can’t be me so yeah me I didn’t have much knowledge. I knew it was AIDS, people die and then it is associated with people who, like maybe prostitutes, drug users, stuff like that, it is a taboo especially in my culture not something people talk about freely”

“The adverts we got were falling tombstones I knew I was going to die”

This, in turn, influenced what parent participants recognized as trauma at diagnosis or early in their stories. This highlights the importance of professionals recognizing trauma in people's stories.

"I think a lot of that came from the trauma that I had faced being a positive person"

"I had a very traumatic experience .... you know with the stigma around HIV it was very difficult for me"

Parents recognize HIV stigma as a key adverse factor in their story which then plays a role in talking to their children about HIV. Here, we see internalized stigma and enacted stigma in action.

"There was a lot of fear a lot of guilt and quite devastating I think because at the time I knew about HIV but because of the stigma that comes with it there's a lot of fear and shame and guilt and feeling like there's no hope for the future"

"It wasn't accepted at all, and I was told by family members .... you will die"

"That is my burden to carry"

Parents tell their stories about how their own relationship with HIV becomes a barrier to talking about HIV to their children. There is recognition in the narratives that parents' negative experiences and experiences of enacted stigma and self-stigma influence their children's journey with HIV.

"It is even within ourselves that is why we cannot talk we stigmatise ourselves then we expect the world to open up"

"I had a lot of fears of telling my child he was positive because of my own fears and experiences"

Parents acknowledged that if they could overcome their own fears, it would be better for their children.

"This generation they have not been exposed to the discrimination that we have experienced so they don't have the negative knowledge about HIV that it is us the parents who have it"

"If we could just let them, we are protecting ourselves we do not want others to find out but if we could just let them, I think in the future it could be better"

"I wish I could have told her earlier"

Parents shared their feelings and emotions in their stories, highlighting fear as an overwhelming factor before HIV was named to their child.

“You fear they will blame you”

“I must admit the build up to that was one of the scariest moments of my life”.

This reflects the heavy burden carried by parents whose children live with HIV. One factor that changes this is naming HIV to their children.

“The best thing I ever did” – naming HIV.

Parents reported that once their child was aware of their HIV diagnosis, the burden was lifted.

“It felt afterwards kind of peaceful like something’s been taken out like put down the load that we’re carrying”

“It was like a weight lifted off your shoulder .... it was like yeah that heavy burden is now off”

“It also made me accept my diagnosis it made me put things into perspective and think we are going to be alright”

The stories of relief and acceptance provide reassuring dialogue, which is important when considering stigma reduction and improved well-being for children and families.

Discussion

This study provides a clearer understanding of the experiences of children living with HIV and their families when HIV is named and has explored the impact of that naming process enabling the voice of children and parents in the UK to be heard.

Growing up with HIV poses unique challenges. This is not comparable to an HIV diagnosis in adulthood because vertically acquired HIV is a health condition from infancy. Hiding a health diagnosis makes HIV incomparable to growing up with other medical diagnoses as this process of purposeful secrecy is not practiced in other fields of child health. The stigma associated dilemma to tell or not to tell (Vreeman, 1963, Pescosolido and Martin, 2015) is experienced by people living with HIV and reflected in the stories shared in this study and illustrated in the quotations in this paper. Sharing of a diagnosis that is associated with multidimensions of stigma is a recognised dilemma that presents people with the debate of secrecy in the hope of community acceptance, versus telling and experiencing public shame and rejection. This study demonstrates that for some parents and young people living with HIV there is no dilemma when it comes to onward sharing; there is an embedded decision to hide, to never tell, to *“make it my lifelong mission to never tell anyone”.* This demonstrates how one learns or decides that they do not fit into societal expectations. Here, we see a glimpse of the hidden world.

Figure One

Figure One caption: A creative piece made by a participant

Figure One Alt Text: Photograph of a mask. The mask has the words “I don’t understand” “Am I going to die” I’m confused” “Will I be ok”. A heart is broken in two and the pieces placed at each side of the nose.

Goffman (1973) questions individual identity by proposing that someone living with a stigmatized attribute, or several others, may have a number of identities. This can be seen in this study through the choices participants made when developing creative pieces as a vehicle to tell their story. Parents and young people often chose to illustrate their story by creating masks and boxes and told of hidden versions of themselves within the narratives. This is a powerful arts-based representation of the impact of HIV stigma.

Figure Two.

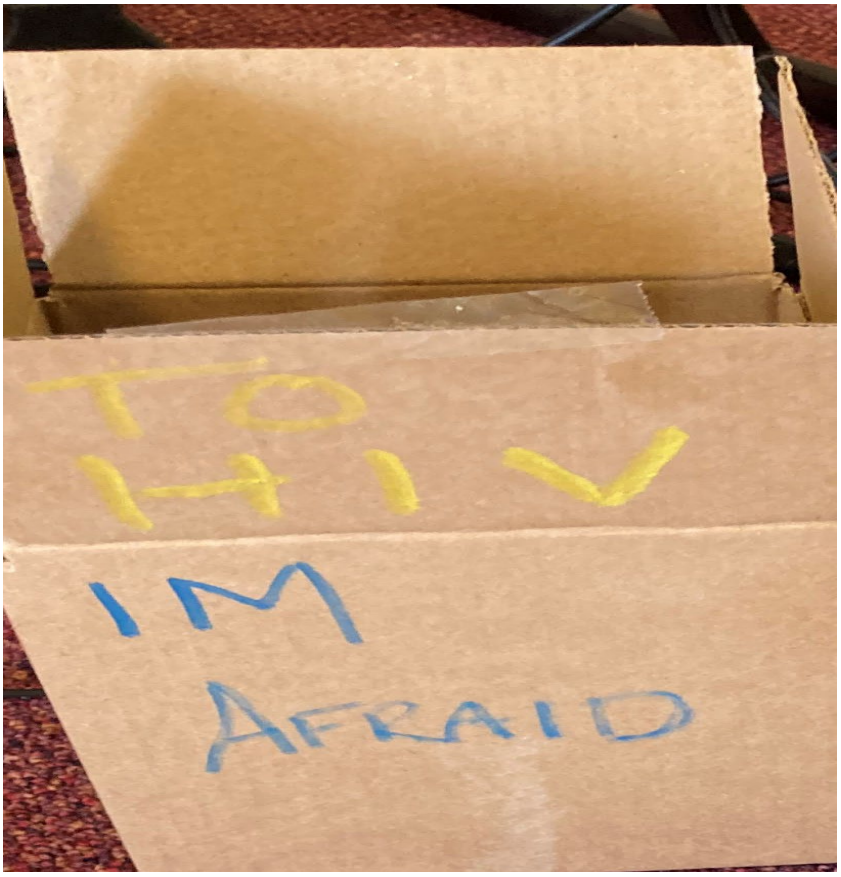

Figure Two caption: A creative piece made by a participant

Figure Two Alt Text: Photograph of a small cardboard box. The box has the words “To HIV” on the lid and “I’m afraid” written on an outside panel. The content inside the box cannot be seen.

The stories participants share in this study exemplify the complexities of HIV stigma in families. The burden of fear and secrecy driven by HIV stigma is illustrated in the narratives. While challenges of onward sharing of one’s HIV diagnosis have been noted, in this study the narratives tell stories of parents’ experiences when HIV is named to their child. The burden of fear is borne by parents. This burden is passed on to children through messages that delay information-giving, prevent conversation and instil secrecy. The dilemma of sharing or naming a HIV diagnosis is both different and amplified when associated with telling a child that they are living with HIV. This scenario involves parents or caregivers and health and social care professionals debating whether, when, and how to tell a child they are living with HIV. We see in the narratives that stigma can prevent naming HIV to children and the implications of not telling include negative consequences on children’s and parents’ physical and mental health.

Young people clarified in their narratives that they wanted to know about their HIV diagnosis from a young age. It is of paramount importance that this information be heard and responded to by health and social care professionals. Stigma dominates barriers to naming HIV to children and this is an overwhelming obstacle highlighted in parents' stories. This study tells of the heavy burden of perceived, anticipated, endorsed and enacted stigma (Birbeck et al, 2019, Earnshaw and Chaudoir, 2009, McHenry et al, 2017, Mesic et al, 2019) leading to fear carried by parents; fear of rejection, fear of blame, and fear that parents say prevents them naming HIV to children. Untangling this web of HIV stigma is crucial, noting that the foundations of stigma can precede a parent's diagnosis because of socially constructed myths and misconceptions associated with HIV, which consequently leads to *"A horrible dark cloud"* arriving at a parent's HIV diagnosis. Parents repeatedly describe their own HIV diagnosis as a *"very traumatic experience";* the relationship between stigma and trauma is illustrated in parents' stories. Recognizing these intertwining factors and their influence in talking to children about their HIV diagnosis opens a window of opportunity to explore trauma with parents early in their journey with HIV.

The heavy burden of stigma-driven fear dominates the lives of parents whose children are living with HIV and unaware of their diagnosis, with one participant talking about naming HIV to her child and stating, *"I must admit the build up to that was one of the scariest moments of my life".* The stories shared in this study paint a clear vision of a parent's landscape before HIV is named to children. This picture changes once the children are informed that they live with HIV. Parent participants shared their experiences after naming and report feelings of relief and acceptance with one parent stating that telling her child was *"the best thing I ever did"*.

It is of significant relevance that amongst the stigma filled heavy burden carried by parents is the recognition that parents pass on their own fears, the same heavy burden of HIV stigma to their children. We can see this as a barrier to naming HIV to children and in the dialogue with children and young people when they are aware of their HIV diagnosis.

Lorde (1984) proposes that silence immobilizes people and urges them to consider a move to speak truthfully rather than being driven to silence:

> "We can sit in our corners mute forever while our sisters and ourselves are wasted, while our children are distorted and destroyed, while our earth is poisoned; we can sit in our safe corners mute as bottles, and we will still be no less afraid" (Lorde, 1984).

HIV silence is recognized in families, including in the family home, and is noted to affect adherence to treatment in children growing up with HIV (Fields et al, 2017). In this study, HIV silence in the family home was highlighted in the voices of young people. Young people

share their experiences of not knowing why they take medication, of the process of hiding medication and of the messages to *"keep it a secret".* HIV silence is seen in the family home in young people's stories: *"not at home, not a conversation in my home".*

To better support children and families living with HIV a deeper understanding of these barriers is required. The data illustrated that HIV stigma causes trauma, creates fear and drives silence. This socially constructed, multidimensional stigma complex dominates parents' decisions associated with talking to their children about HIV. Parents' feelings and emotions were transferred to their children. We identified this as intergenerational stigma. Intergenerational stigma is illustrated in this study by the cyclical process of *"passing on our fears"* from parents to children.

Intergenerational stigma – a new concept

Goffman (1973) discussed tribal stigma that can affect all members of a family but this discussion is linked to specific family characteristics such as skin colour or religion. HIV, in the context of children and young people, is often a health condition affecting a number of family members; however, HIV is not a visible attribute, although evidence notes that there may be occasions when people make assumptions associated with growth and weight (McHenry et al, 2017).

The social construction of stigma has negative effects on families and family units within society (Fife and Wright, 2000). Mendelsohn et al (2022) noted the process of intergenerational knowledge transfer within cultures and its role in relation to HIV knowledge and associated stigma. A large qualitative study in South Africa highlighted the fear of sharing an HIV diagnosis within families because of the consequent expected rejection and experiences of rejection. Such experiences are associated with food sharing, which is a culturally important family experience (Okoror et al, 2007), highlighting the detrimental role of internalized stigma within families. While this illustrates internalized and enacted stigma within families it does not reveal the experiences of children living with HIV.

The SKETCH study identifies experiences of all reported components of stigma and an association with tribal stigma as a family concept. However, the findings unravel a new component of stigma described as intergenerational stigma. This finding indicates that interventions to address the issue of intergenerational stigma are needed. While stigma interventions have been reported (Rao et al 2019), a systematic review concluded that there are limited intervention frameworks that focus on children and young people and proposed that future interventions need to jointly consider children, young people and adults (Hartog et al, 2020). UNAIDS (2023) provides a practical guide to stigma-reducing interventions; however, while family interventions are noted as important, there is only one identified

intervention linked to young people, and no consideration of children younger than 15 years of age. Denison et al (2022) conducted a randomized control trial that recruited adolescents over 15 years of age and caregiver pairs, introducing a peer support model to the intervention arm. Treatment adherence was not significantly different in either arm of the study, but a reduction in self-stigma and social isolation was observed among those receiving peer support as part of the trial. However, there is a gap in the understanding of intergenerational stigma and the absence of appropriate support.

When delaying naming remains a common practice, it directs children and young people to step in to a funnel of stigma-driven harm. The narratives in this study illustrate the negative impact of intergenerational stigma, and the overwhelming burden of secrecy carried by both parents and children. This study calls for an urgent need for changes in practice and new resources.

Limitations

Whilst participant demographics led to stories that told of experiences in several different countries, those recruited were living in the UK which consequently restricts generalizability. The number of participants is reflective of qualitative research; however, the sample size must be considered. Additionally, we note that not all people living with HIV access voluntary sector support and therefore some experiences may not have been captured.

Recommendations

HIV related stigma negatively affects lived experiences and can detrimentally affect the health outcomes of children, young people, parents and families living with HIV. It is also clear that HIV acceptance is vital to thrive and survive. While barriers are acknowledged it is essential that appropriate support to explore HIV impact and trauma with parents should become normal practice. It is imperative that parents' stories be heard by other parents who experience the dilemmas associated with naming HIV to children. The authors of this article argue that facilitating open communication about HIV and naming HIV to children at a young age can halt the cyclical burden of intergenerational stigma.

As demonstrated in this study, arts-based narrative inquiry is an inclusive, accessible and culturally sensitive methodology that has resulted in globally transferable findings across different settings. We recommend arts-based approaches as a means of hearing children's and adult's lived experiences, acknowledging that it is not only an inclusive approach but supports the therapeutic benefit of storytelling. The importance of recognizing the cumulative complexities of HIV stigma for children growing up with HIV is imperative to make the necessary steps to reduce the stigma's impact. The findings of this study identified

intergenerational stigma as a cyclical process, reflective of Lewin's (1947) recognition of social life following circular processes. Lewin (1947) proposed that one must consider the inner and outer influences of the current situation to change future destinations. Health and social care professionals must recognize parents' or caregivers' experiences and consider trauma-based therapy as part of stigma reduction during their journey with HIV. Parental fears must be acknowledged with empathy and therapeutically untangled. The voices of children must be heard; children want to know about their HIV diagnosis at a young age. Parents' experiences of relief and improved wellbeing after their child is made aware of their HIV is a key driver of early naming of HIV to children. The continuation of secrecy and hiding of a child's diagnosis fuels the cycle of intergenerational stigma, which is detrimental to the health and well-being of children living with HIV and their parents. It is time to change practice. This study will inform the direction of practice in the UK recommending trauma informed care for parents. We recommend that early naming of HIV occurs, and open communication is promoted and facilitated in health care settings and in the family home. HIV associated public knowledge strategies must continue to be promoted to reduce HIV myths, misconceptions and public stigma. Further research exploring prevention of, and restorative therapeutic practices for reducing harm of HIV-related intergenerational stigma is required. Research must examine the extent to which HIV related stigma affects children, young people and families' journeys with their HIV diagnosis in terms of physical and mental health. The family unit, including children and caregivers, must be considered in anti-stigma approaches and future frameworks.

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All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. (Warburton, K., Mulongo, P., Satchwell, C., Olive, P. & Farrier, A.)

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