GROWING TOGETHER FOR HEALTH AND HAPPINESS

It's Time to Tell: How Early Naming of HIV to Children Improves Adolescent Wellbeing and Reduces Self-Stigma

Background

Historically children and young people living with HIV have been informed of their diagnosis during adolescence. Informing adolescents in their formative years led to greater psychological stresses and challenges, poorer adherence and increased mental health difficulties. Young people report that they wanted to know about their HIV diagnosis in early childhood (Warburton,2024) yet early conversations and open communication is not yet standard global practice (Warburton et al, 2022). Chiva state that children living with HIV in the UK should know about their diagnosis no later than 9 years of age.

Methods and Approach

An arts-based narrative inquiry explored how children living with HIV and their parents experienced their child learning about their HIV.

16 young people and 10 parents were recruited to focus groups via voluntary sector organisations in the UK.

Participants used arts to create something of their choice. The creative piece gave participants a voice enabling them to share their untold stories.

The focus group discussions were recorded. Reflexive thematic analysis was used to analyse the data.

Insights provided from the inquiry were used to inform professional practice at Chiva. Working in partnership with clinic teams, community-based support officers began naming HIV to younger children (age 5-7) in the community in the context of family support. Incorporating creative approaches such as use of pictures, stories, balloons, videos, and developing up-to-date and age-appropriate naming resources.

"Tell us please"

Children's voice

"Telling you about your HIV was one of the best things I did but I must admit the build-up was one of the scariest moments of my life".

Parent's voice

"I've made it my life mission not to tell anyone"

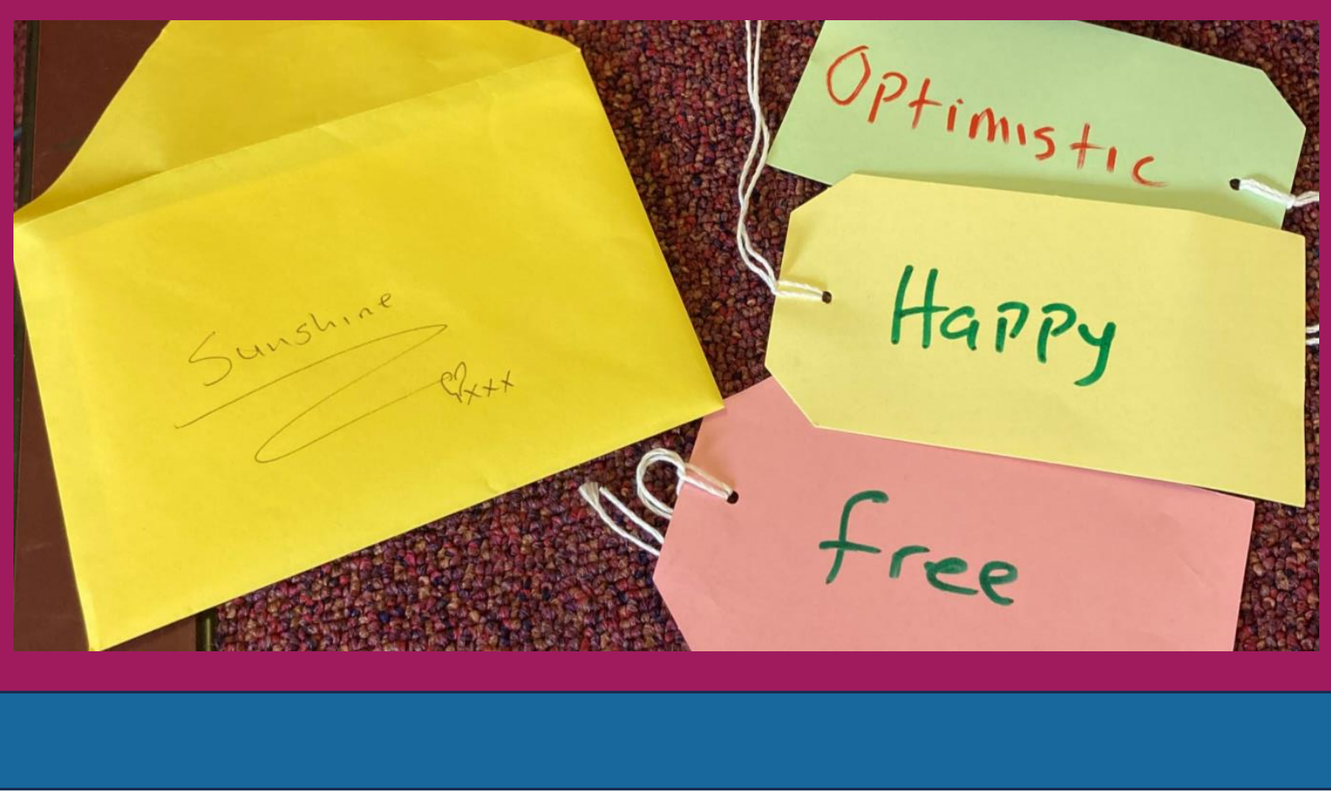
Adolescent's voice

Results and Findings

- Children, young people and parents report experiences of stigma and self-stigma associated with their HIV diagnosis.
- Parents worry about naming HIV until the child knows and must be supported on this journey.
- A holistic approach to naming HIV and open communication in the home, community or clinic reduces self-stigma and fear.
- Naming HIV to younger children has illustrated that self-stigma is reduced. Children are empowered to understand and manage their health and play an active role in their healthcare.
- Creative approaches can support understanding.

Conclusions and recommendations

- Adolescents report experiences of self-stigma and fear associated with their HIV diagnosis. Self-stigma has a negative impact on mental health and wellbeing.
- Young people and parents call for open communication, and clear and consistent language when talking to children about HIV.
- Open communication and naming HIV in early childhood reduces secrecy, hiding and consequently self-stigma.
- Healthcare professionals should plan early to name HIV to younger children and encourage open communication in families thereby supporting resilience, family coping and lifelong approaches to supporting young people's wellbeing.
- Effective multi-agency collaboration between healthcare teams, NGOs and public sector professionals can ensure that healthcare for children and young people growing up with HIV continues to innovate and develop. This ensures that the voices and experiences of children and families are fully incorporated into the care and support provided.
- Addressing the impact of HIV-related stigma should be a key priority in all areas of healthcare and support.



Warburton, K., Naver, L. Houghton, J. & Fatikhova, K. (2022) Talking to children about their HIV diagnosis: a discussion rooted in different global perspectives. **British Journal of Nursing.** Vol. 31 No.1 Supp. Pp.3-7.
Warburton, K. (2024) An arts-based narrative enquiry: Naming HIV to children - young people and parents share the stories that matter to inform future practice. **HIV Medicine.** Vol. 25. Pp: 15.

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