

“It’s all down to stigma really”: Perspectives of young adults living with perinatally acquired HIV, their social network and healthcare professionals on barriers and facilitators to sharing an HIV status.

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Introduction

- Young adults who were born with HIV face several challenges, including adhering to antiretroviral therapy, managing the risk of onward HIV transmission and maintaining their well-being.
- Sharing one’s HIV status with others may assist with these challenges by facilitating emotional and practical support. Rates of HIV status sharing are, however, low in this population.
- There are no existing interventions focused on sharing one’s HIV status for young adults born with HIV. This study was part of a larger study developing such an intervention (called HEADS-UP).
- The objective of this study was to further understanding of the sharing process and provide insight into both barriers and facilitators of sharing in this population.
- This is the first qualitative study to report on both barriers and facilitators to sharing among young adults born with HIV from the perspective of friends, family and partners.



“People don’t understand fully what HIV is and like how you actually get HIV and how it’s passed on etc. So that’s probably the major reason why people don’t want to share...it’s probably the fear of being left out or out of place, alienated. Yeah.”

- Friend

“I just felt like I got to a point in my life where I was comfortable with them kind of knowing. It’s kind of like I didn’t want to, not hold anything back, but I didn’t want there to be any like barriers or secrets between me and them. That was kind of it really.”

-Young person living with HIV

Results

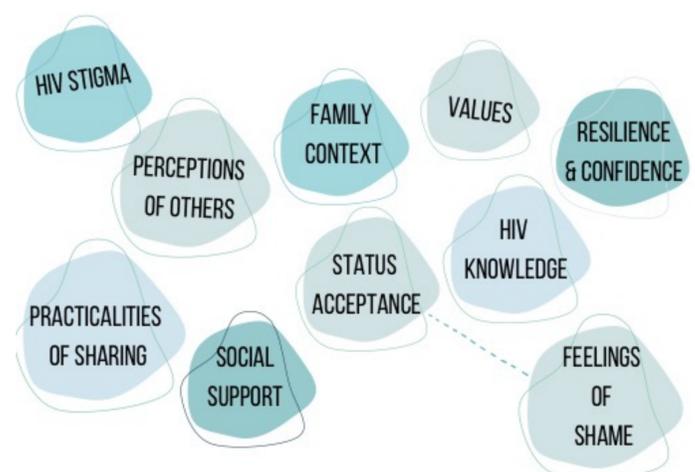
- Thematic analysis indicated several themes. These included (1) HIV Stigma, (2) Feelings of shame, (3) Perceptions of others, (4) Social support, (5) Status acceptance (6) Practicalities of sharing, (7) Resilience and confidence (8) Family context, (9) Values, (10) HIV knowledge.
- HIV stigma as a barrier to sharing was a common theme. This included the internalisation of societal negative attitudes towards HIV.
- When describing barriers to sharing their status, a number of participants talked about a lack of knowledge about HIV. They pointed out a lack of knowledge and awareness in the general public but friends and partners of people living with HIV also admitted that they themselves had not been educated about HIV until someone shared with them.
- The majority of participants living with HIV mentioned their families. For some, their families were a great source of support, but others talked about the family context as a barrier to sharing due to their attitudes of secrecy and shame around HIV and not wanting to share their mothers’ status.
- Young people, their social networks and professional participants talked about the importance of overcoming feelings of shame and accepting their status before sharing it with someone.
- Young people’s perceptions of others were described as having a really import impact on whether they felt they wanted to share their status or not. If someone was perceived as understanding or trustworthy, they may be more likely to share with them. Conversely, if they felt someone had negative attitudes towards HIV for example, they may fear that they could be rejected by this person and therefore would be less likely to share with them.
- Social support was another very common theme, with some talking about sharing in order to receive support from someone, and others saying that having support from accepting family or friends helped them feel confident to share with others.
- Participants also talked about their values playing a part in whether they felt they wanted to share or not. For example, some participants talked about “honesty” being an important value, meaning they did not want to lie to a friend or partner, or would feel guilty about keeping a secret.

“the stigma overrides the feeling of wanting to share, I think it definitely does. Because ideally everyone would want to be honest about themselves and let everyone know every part of their identity, but unfortunately the fear of reactions and how people judge others really locks people away from doing a lot of things .”

- Young person living with HIV

“I think it’s almost generational. From my generation accepting and tolerance and understanding, it’s a very different world from what say my parents grew up with and my grandparents.”

- Partner



Conclusions

- These in-depth interviews identified a number of barriers and facilitators to sharing one’s HIV status, highlighting a number of ways in which young people living with HIV could be supported.
- These results informed the development of an intervention to support young adults in making decisions about sharing their status.
- Outcomes of this study will provide valuable information to guide further HIV sharing or sharing decision making support for young adults born with HIV.

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