



THE UNIVERSITY *of* EDINBURGH

“Everybody's different, everybody's got different needs”

Transition to adult healthcare services and the role of social support—the views of young adults living with HIV in Scotland.

Executive summary

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“Everybody's different, everybody's got different needs... there'll be some people that find it so hard, emotionally, to live with HIV... then there's other people living with HIV... there's other things that they need help with... like finding somewhere to go when things get tough at home”.

As the nature of HIV has changed in Scotland, so has the cohort living with HIV. There is now a group of young adults living with perinatally acquired HIV, who were not first expected to survive into adulthood. With such gains come new challenges, including the transfer of these patients from paediatric to adult healthcare. In other chronic illnesses, transfer has been affiliated with poorer health outcomes such as reduced clinical attendance and medical adherence. Young adults living with perinatally acquired HIV have additional aspects to contend with such as stigma, secrecy, disclosure and risk of transmission. Thus, a planned process of transition that meets the unique needs of these young adults is pertinent to sustain their engagement in healthcare and foster independence in responsibility of care. Otherwise, there is a threat to gains achieved including: virologic suppression, limits to resistance to therapy and reduced onward sexual or vertical transmission. This report explores the views and experiences of young adults living with perinatally acquired HIV in relation to the transition process, as well as a small sample of perspectives of practitioners who work closely with young adults during transition.

An initial literature review explored the prevailing current thoughts on transitions for individuals living with HIV. Then individual semi-structured interviews were carried out with eight young adults living with perinatally acquired HIV (median age = 19.5 years) and two healthcare practitioners.

Key findings include:

- Young adults that find out their diagnosis at a late age tend to have difficulties in accepting or understanding their HIV status which consequently affects the successfulness of their transition process. (Particularly if finding out occurs just before transfer).
- Young adults wish to be treated and perceived as ‘normal’. Most young adults reconcile being ‘normal’ as being perceived as HIV-free and often discontents was shown with respect to adult healthcare as they are pervasively faced with HIV in this setting.
- The experiences and views of young adults are deeply intertwined with HIV-related stigma and furthermore, the wider ethos of discrimination seen towards certain groups, such as Black African’s, who are relatively overrepresented in terms of those living with HIV in the UK and Scotland.
- Coordination between the paediatric and adult healthcare teams is appreciated by young adults, and starting with joint consultations can ease the anxiety related to transfer.

- All young adults valued that they were seen as whole people, not defined by their HIV status, at Waverley Care. The help they got from Waverley Care was not solely HIV-related.
- Social support organisations counter the social isolation many young adults had suffered from by providing a safe space without the need for young adults to put themselves under self-surveillance.
- Peer support, ensuing from Waverley Care, works to promote empowerment of young adults to take control of their healthcare and look towards a positive future, contributing to a successful transition in healthcare.

Recommendations include:

- Young adults should get a choice of where their healthcare needs are met, including a hospital setting or a sexual health and reproductive clinic.
- Effort should be made to foster an understanding and acceptance of illness before physical transfer occurs.
- Young adults need accessible information regarding the practicalities of adult healthcare and support with knowing exactly what they can and cannot do with regards to work, the law and relationships.
- All sectors that engage with young adults living with HIV need to recognise the heterogeneity amongst different young adults and the different kind of support that each individual may need.
- Of utmost importance is that adult healthcare settings are places of non-judgement and comfort for young adults to avoid negative repercussions. To ensure this non-specialised staff should also receive appropriate training in this regard.
- The context of young adults' lives is extremely important and transition practice must be situated against this backdrop.
- The process of transition should be made clearer to individuals experiencing it, because if they are unaware, negative consequences remain difficult to negate.
- Voluntary organisations that provide social support should be utilised further through transparency of healthcare practice. Such organisations can be especially helpful in facilitating acceptance and understanding of HIV and also understanding of the healthcare transition process and what is required of individuals in this respect.