

EXPLORING THE ROLE OF FAMILIES IN HIV TREATMENT NARRATIVES, DECISIONS AND PRACTICES

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Background:

As the medical management of blood borne viruses undergoes rapid change, the families of those affected are also living through and responding to those changes. Yet both research and policy responses remain focused on the individual, with less known about the role that families might play in supporting HIV treatment initiation and adherence over time.

Methods:

This presentation draws on a sub-set of 33 interviews from the qualitative 'my health, our family' study, the first to document the experiences of families (broadly defined) affected by HIV, hepatitis B and hepatitis C in Australia. Focusing on participants who were either themselves living with HIV (n=16), had a family member living with HIV (n=9), or who occupied both of these 'primary' and 'family' roles (n=8), our analysis reviews key themes related to HIV treatment.

Results:

Treatment formed a central component of family narratives about HIV. Disclosure to family often relied on a narrative of treatment efficacy, e.g., 'there's no need to worry, treatment will keep me well and my partners safe'. Many family members, of diverse ages and backgrounds, sought to educate themselves in HIV science, and provided emotional and/or practical support regarding the initiation and maintenance of treatment. Parental, sibling, and intimate partner relationships all provided examples of valued support, but could also be experienced as interfering or burdensome. Family involvement in treatment decisions and practices could therefore be experienced either as a form of care or a source of tension.

Conclusion:

While biomedical therapies can provide family members with a concrete strategy for demonstrating support, family involvement is not welcomed by all. It is critical we better recognise and strengthen the role of families in supporting HIV treatment use, given the uniquely persistent contribution of family relationships through the many years in which people now live with HIV infection.

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