

## **OPEN DOORS AND FAMILY SECRETS: NEGOTIATING COMMUNICATION AGREEMENTS AMONG FAMILIES AFFECTED BY HIV, HEPATITIS B AND HEPATITIS C**

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**Background:** While there is a broad literature on disclosure and other forms of communication about blood borne viruses (BBVs) among people living with HIV, hepatitis C, and to a much lesser extent, people with hepatitis B, far less is known about how this is negotiated among their broader family networks.

**Methods:** Qualitative interviews (n=52) were conducted between 2017-2018 with people who had been diagnosed with HIV, hepatitis B and/or hepatitis C in Australia, as well as family members. Thematic analysis identified a common theme of 'secrecy, shame and stigma', which included a diverse range of communication agreements which participants had negotiated within their family relationships.

**Results:** Very open agreements about who was permitted to speak about the BBV, with whom, in which context and for what purpose, were negotiated in a few cases, although not in the case of hepatitis B. Openness was particularly valued among those contributing to HIV and hepatitis C treatment awareness and advocacy. However, far more conservative arrangements featured in many other families, with only selected people brought into the circle of confidence, and clear expectations established for keeping this sometimes 'shameful' secret confidential. We also heard stories of communication agreements being renegotiated over time, but this did not always mean a progression towards more open communication.

**Conclusion:** While our method means we can only review how family communication agreements were described at one point in time, our analysis provides an important insight into the complex range of people who continue to be affected by a BBV diagnosis, even in a time of increasingly effective treatment and management. It is essential that the social impacts of stigmatized blood borne viruses continue to be recognized and addressed, including those hidden 'others' who can become implicated in maintaining complex practices of secret-keeping on behalf of their loved ones.

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