

HIDDEN CARERS? UNDERSTANDING THE NEEDS OF INFORMAL CARERS OF PEOPLE WITH HIV IN THE CONTEMPORARY TREATMENT ERA

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Background:

The role of informal carers in supporting people with HIV was well recognised in the first two decades of the epidemic. They continue to play an essential role in the HIV response of the global south. However, in better resourced settings, such as Australia, the role of informal carers has become increasingly hidden and we know little about their contemporary contributions and support needs.

Methods:

A scoping review documented what is known about the formal support, policy and service needs of informal carers of people with HIV in developed nations, as published in English-language journals between 2004-2016. Qualitative interviews were conducted between May 2017–April 2018 as part of the ‘my health, our family’ study with 33 people either living with HIV (n=16), with a family member living with HIV (n=9), or occupying both of these roles (n=8).

Results:

Integrating both analyses, we can see that informal care relationships continue to be significant for many people with HIV, including intergenerational and same-sex relationships. Care ranges from emotional support to help with daily life, but most common is support regarding medication and health service use. These carers have similar needs to other carers, encompassing individual (emotional), relational (family, social), and community (schools, services) levels, but these needs mostly go unrecognised by services, practitioners and policymakers.

Conclusion:

Despite the post-crisis and ‘normalisation’ sentiments common to the contemporary HIV response, many people with HIV in developed nations still have care needs, and the informal care provided by friends and family remains largely hidden. While the value placed on HIV self-management may discourage carers from naming what they do as ‘care’, we need to ensure that policies and services are valuing and meeting the support needs of informal carers of people living with HIV.

Disclosure of Interest Statement:

The Social Policy Research Centre and Centre for Social Research in Health are supported by UNSW Arts and Social Sciences. This research was supported by an Australian Research Council Grant [DP160100134: Critical Perspectives on Serodiscordance in Family Life]. No pharmaceutical grants were received in the development of this study.