



Hidden carers? Understanding the needs of informal carers of people with HIV in the contemporary treatment era

Never Stand Still

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Introduction

- Role of families in providing care and support for people with HIV was well recognised in the first two decades of the epidemics faced by economically-developed countries.
- In Australia, with the relative success of prevention programmes, the role of families in care and support has become increasingly hidden
- We know little about their contemporary contributions and support needs.
- We address this gap by presenting the results of:
 - A scoping review of the formal support needs of unpaid carers of people with HIV in developed nations; and
 - Qualitative interviews with people with HIV and their families.



Background

- **Carers** are family members or friends who provide unpaid care and support for a person with a chronic illness, disability or frailty due to old age.
- For several decades, there has been greater recognition of the important role of carers, and efforts by policymakers and services to recognise and consult carers, and to meet their support needs.
- But some groups of carers remain 'hidden' from services.
- 'Hidden' carers are people who provide unpaid care but do not think of themselves as 'carers', and are therefore less likely to access support and more likely to have unmet needs.



Background

- Carers may not identify as carers, and remain 'hidden':
 - To protect the identity and independence of the cared for person;
 - Because of stigma and secrecy about the illness or care relationship;
 - Because of the view that support for a relative is just part of family life;
 - Because the types of care tasks they do may not be normatively constructed as 'care', such as *emotional* care tasks; and
 - Because the service environment may render some groups of carers less 'visible'
- We suggest that family members of people with HIV are one such group of 'hidden carers', largely invisible to services



Question and aim

- Drawing on data from an ARC Discovery Project *My Health, Our Family* that seeks to understand the 'family life' of blood borne viruses, this paper seeks to answer the questions:
 - What is known about the formal support, policy and service needs of carers of people with HIV in the contemporary HIV treatment era?
 - What might the barriers be to their service use?
- By answering these questions, we aim to:
 - Increase the visibility of this hidden group of carers; and
 - Develop an evidence base that can inform the policies, services, and service practices that can support carers of people with HIV



Method

To learn about the support needs of family carers of a person with HIV, we:

- Conducted a scoping review of what is known about the support needs of family carers of people with HIV
 - ProQuest and Scopus using a combination of the following terms: “Carer*” AND “Hepatitis B” OR “Hepatitis C” OR “HCV” OR “HIV” OR “blood borne virus*”, and searching within article title, abstract and key words. Repeated with “caregiver” instead of “carer”
 - Journal articles published between 2004 and 2016, with a focus in Australia, New Zealand, Canada, United States of America (USA), United Kingdom (UK) and Western & Northern European countries
 - Narrowed down sample
 - Consulted with key informants in community and clinical organisations
- Conducted qualitative interviews (mainly but not only in NSW):
 - people with a primary lived experience of HIV
 - people with a family member who is/has been affected



Participant sample

May 2017-Sep 2018	Totals
Primary perspective	15
Family perspective	10
Primary AND family perspective	10
	35

- **Age:** 15-61 years; < 30 (7), 30-49 (9) 50-69 (15), 70+ (4)
- **Diagnosis year** (primaries): childhood (2), 1980s (3), 1990s (5), 2000-09 (11), 2010+ (4)
- **Currently living:** Metro (21) **Regional (14)**
- **Gender identity:** **female (19), male (16)**
- **Sexual identity:** **heterosexual woman (16) or man (6), gay man (9)**, lesbian (1), bisexual woman (1) or man (1), not provided (1)
- **Region of birth:** Australia (20), Africa (6), other English-speaking nation (5), Asia (2), Europe (2)
- **Relationship to person living with HIV** (families only): same-sex partner (male) (4), mother (3), opposite-sex partner (3), child (4), sister (3), step parent (2), close friend (1)



Findings: what kind of care are they providing?

- Care of people with HIV was **diverse**:
 - emotional support
 - instrumental help
 - coordination of health and other services
 - performing activities of daily living
- Providing **support with treatment use** was central
- Managing **stigma and secrecy** also important
- Another form of support was **'monitoring'** for changes in health and wellbeing



Findings: what kind of care are they providing?

*When I was sick in hospital, it's like (my partner) **kicked into another mode**. He was always there. Always **making sure the nurses and doctors were doing the right thing**, with my aunty's help. So my aunty was there the whole time. So this was like that first example of what happens **when you get really sick**, how **your whole family interacts with doctors**, and is, **how they're there for you**, and all that type of thing"*
 (Ryan, Participant 33, Gay M)

*When she's going to stay at a friend's place, you know, she's always gotta take her tablets with her... And I used to, **instead of giving them the medicine** so they could Google it, I used to always **have them already prepared in a syringe**, and all they had to do was give [my daughter] the syringe and she'd just, you know, swallow the medicine from the syringe. So **they never actually saw the label on the bottle**" (Lucy, Family member 53 Het F)*



Findings: what are their support needs?

- **Emotional support:** Depression, anxiety, stemming from worry about person with HIV, family pressures associated with HIV, social isolation, and worry about their own health.
- **Intimate and family relationship support:** Pressure placed on family and intimate relationships as a result of living with and/or managing HIV in the relationship.
- **Community and peer support:** Some experienced stigma, felt isolated from friends and networks, and found it difficult to establish relationships with new people, resulting in stress, depression and grief.
- **Information about HIV and training/support to build caring skills:** Carers felt that uncertainty about the course, transmissibility and treatment of HIV was a source of concern, worry and family conflict or strain.
- **Practical support:** Respite, or help around the house, during periods in which their family member or friend was very ill.



Findings: what are their support needs?

From the very beginning I said to people, “I wanna be the one to tell, okay? So if anyone finds out about it I’m the one.” But that didn’t work... Both my brothers had to tell someone else. And I realised through that experience... is that when you tell someone you need to give them someone else to talk to, you know?” (Melissa P 48 Bi F)

I had a very great friend who was a wonderful friend to me but I took almost a year or more than a year to be able to tell her. But she burst into tears when she heard the news and she was wonderful with me, and just said, “Why didn’t you tell me sooner?” But it’s so hard to know how people are going to judge the whole story. So you keep it to yourself more than anything. These counsellors were wonderful. There was never any judgement from them (Rosemary F 73 Het F)



Findings: What are the barriers to service use?

- **Gaps in services/lack of services**
 - Lack of services for carers of people with HIV across different areas of potential support
- **Lack of recognition by services and practitioners**
 - Low recognition by services and practitioners of role of carers, including limited family-centred support services.
- **The role of stigma**
 - Greatest barrier for carers was social stigma associated with HIV, which discouraged many from accessing informal and formal support.



Conclusions

- Carers of people with HIV in economically developed countries such as Australia have a number of **support needs**, which may be **largely unmet**, at **individual** (emotional), **relational** (family, social), and **community** (services) levels
- **Gaps were identified** in services specifically for carers of people with HIV, and **lack of recognition** of families and carers in HIV services
- **Stigma and discrimination complicate support seeking** and service engagement among carers
- At the broader level, **discourse of independence** associated with new HIV treatment era **may marginalise support** by family and friend carers.
 - Also underplays importance of carers in supporting people with HIV with *new* forms of care and treatment, as well as carers of people with HIV who have high care needs despite new treatments



Further research

- More research needed on role that public health discourses about HIV might play in marginalising support provided by carers for people with HIV. This marginalisation may make it more difficult for *carers* to self-identify, and for *services* to recognise and address the needs of carers in their policies and practices.
- Further research needed on ways services can work more effectively with their families and carers of people with HIV
- Scoping review revealed a gap in the research literature on the needs of carers of people with hepatitis B and hepatitis C, infections whose stigmatised nature and impact on morbidity are similar to that of HIV. More research is required in this area in order for policies and services to better meet the needs of these hidden groups of carers.



Further comments or questions:

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