Access to healthcare services for people living with HIV experiencing homelessness – a literature review

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KEY WORDS

HIV, PLHIV, assertive outreach, community nursing, engagement and retention in HIV care

ABSTRACT

Objective

People living with HIV (PLHIV) who are homeless or at risk of homelessness experience significantly worse health outcomes than those in stable housing. They are more likely to be diagnosed late, use substances, engage in high-risk sexual activities and have difficulty adhering to treatments. This review identifies strategies described and evaluated in the international social science literature which can improve access to HIV-treatment and care for PLHIV who are homeless or at risk of homelessness, to inform policy and service development in Australia.

Setting

The principle research question addressed in this review is:

 What strategies enhance the ability of PLHIV who are homeless to access health care services, in particular community nursing services?

A literature review of social science research relating to the research question in the international and Australian contexts was conducted.

Primary argument

No literature was identified that addressed access to community nursing services for PLHIV experiencing homelessness in Australia, and very little internationally. Community-based nursing organisations are well-placed and experienced in engaging marginalised groups in health care. Specific interventions need not always be developed: rather, better use could be made of existing services that utilise assertive outreach models of care and co-location with other services.

Conclusion

HIV-specialist community nursing services could be better integrated with homelessness services to enhance access to care, link PLHIV into the health system and keep them engaged in care. The absence of research on engagement with HIV specialist community nursing services demands exploration.

INTRODUCTION

By end 2014, there were approximately 27,000 people living with HIV in Australia; over 70% of these are men who have sex with men and approximately 10% are women. Fewer than 2% can be attributed to sharing injecting equipment (The Kirby Institute 2015).

Data is limited on the numbers of homeless people living with HIV in Australia. However, the Australian Bureau of Statistics (ABS) 2014 General Survey indicated that lesbian, gay or people of 'other' sexual orientation were more likely to report at least one episode of homelessness than were heterosexual people (ABS 2014), and a 2013 study from the University of Adelaide concluded that lesbian, gay, bisexual, transgender and intersex (LGBTI) people are over-represented in homeless populations (Oakley and Bletsas 2013). Homelessness and unstable housing amongst youth have been associated internationally with increased HIV infection risk (Marshall et al 2009).

In some Australian states, specific housing associations have been established representing the interests of people living with HIV, indicating that housing and homelessness are significant concerns for this population. For example, in Victoria, the AIDS Housing Action Group was established in 1990 and in a recent parliamentary inquiry, this group described specific issues such as same sex domestic violence, refugee and asylum seeker status, stigma, discrimination and violence against people living with HIV within public housing, the impact of living with a chronic, complex and life threatening illness, social isolation and ostracisation from family and community, ageing with HIV and a range of other issues potentially contributing to housing instability and homelessness (AIDS Housing Action Group 2011).

Internationally, HIV prevalence is highest among the marginalised (Wakeman et al 2009). There are high rates of homelessness amongst PLHIV and high rates of HIV amongst the homeless (Cheever 2007; Douaihy et al 2005). PLHIV who are homeless or at risk of homelessness experience significantly worse health outcomes than those in stable housing (Cheever 2007), and are at greater risk of hospitalisation (Nosyk et al 2007). Homeless PLHIV are more likely to be diagnosed late (Nelson et al 2010), to use substances, engage in high-risk sexual activities and have difficulties with treatment adherence (Roy et al 2011; Friedman et al 2009; Stein et al 2009; Marshall et al 2008; Metraux et al 2004). These factors mean they can risk transmitting HIV to others, with reduced access to HIV prevention education (Stein et al 2009). The prevalence of HIV infection amongst the homeless has been estimated to range from 0.3% to 21.1% (Beijer et al 2012). One study conducted jointly in Australia and the United States of America (USA) indicated that 2% of homeless youth in both countries self-reported that they had HIV infection (Milburn et al 2006), and rates of up to 20% have been reported in the USA (National Coalition for the Homeless 2007).

It is also known that in the USA at least 20% of PLHIV are unaware of their infection with much higher figures amongst the most marginalised (Chen et al 2012). In Australia, it is estimated that about 14% (range 11-21%) of all HIV infections are undiagnosed (The Kirby Institute 2014). Access to care for this group is a significant public health issue worldwide (Beijer et al 2012).

It is documented that homeless PLHIV experience reduced access to health care including HIV primary care, and a range of interventions has been explored to improve or increase their access to HIV care, and to retain them in care (Thompson et al 2012). Little published research deals specifically with their access to specialist HIV community nursing services.

In the Australian setting, the Victorian HIV Strategy states:

'Sub-groups of people with HIV/AIDS continue to experience difficulties in accessing treatment care and support services. Agencies are encouraged to identify vulnerable groups of people with HIV/AIDS and to

design a range of strategies and services to better meet their needs. These strategies include:

- Making existing services more flexible and available to people from marginalised sub-groups.
- Developing collaborative partnerships between HIV/AIDS services and mental health, migrant health, homeless youth, Needle and Syringe Programs and women's health services' (Victorian Department of Human Services 2002, p26).

Community nursing services in Australia are often central to linking people into HIV medical care and primary health care. In several states, community nursing services have close partnerships with AIDS Councils (referred to internationally as AIDS Service Organisations [ASOs]) (Crock and Frecker 2008). Homeless PLHIV may come in contact with ASOs and be linked in with community nursing organisations, or they may come in contact with the nursing service first through specialist programs or following hospital admission. Enabling them to access HIV care and retaining them in care can be challenging, but community nursing services with expertise in HIV are well–placed to play a significant role in engagement in HIV primary care (Purcell et al 2006).

The principle research question addressed in this review is:

 What strategies enhance the ability of PLHIV who are homeless to access health care services, in particular community nursing services?

Secondary questions considered for this review include:

- What are the barriers to access to health care services for PLHIV who are homeless?
- What factors contribute to retention in care for PLHIV who are homeless or at risk of homelessness or marginalised for other reasons?

SEARCH STRATEGIES

A literature review of social science research relating to the research questions in the international and Australian contexts was conducted (2002-2012). The search strategy included the use of the electronic databases Global Science, SCOPUS, Social Work, PsycINFO, CINAHL and the Australian HIV/AIDS Database. Search terms used were: HIV and/or AIDS, homeless or homelessness, access to HIV care, access to services, barriers to access, and community nursing. Further research was conducted seeking publications on the National Centre in HIV Social Research website and the Australian Federation of AIDS Organisations' websites, including the journal 'HIV Australia'.

Little information on HIV and homelessness in Australia was found, hence this review draws principally from international literature. No literature was located that specifically addresses strategies to enhance access to HIV specialist community nursing, so the focus was broadened to include strategies to enhance access to and engagement with HIV primary care and health services generally for the homeless and for people marginalised for other reasons such as injecting drug use, minority status, mental health problems, or all of these. The terms 'retention in HIV care', 'engagement' and 'marginalised' in various combinations were subsequently added to the original searches. Twenty one articles were located that were considered relevant to the subject area, and of these, eight were considered relevant for more in–depth review to address the research questions.

SUMMARY AND ANALYSIS

Two studies reported on research into PLHIV living in single room occupancy hotels (SROs). SROs in New York City are used as emergency housing for homeless PLHIV.

The first of these examined service utilisation patterns amongst chemically dependent homeless PLHIV to evaluate the program theory that engagement with outreach services is 'a mediating variable that increases service utilisation' (Shepard 2007, p26). This study comes from a positivist paradigm, although it examined a model of care and outreach (harm reduction) that contrasts with a medical model and promotes empowerment and self-determination (Shepard 2007).

The population studied was a group of homeless PLHIV with a history of chemical dependence residing in SROs in New York City. Two cohorts were compared – individuals who were engaged through 'harm reduction outreach' and those who 'walk-in' to a drop in centre (Shepard 2007, p26). Outreach was defined as a model including: crisis intervention; addressing problems; skills building; education; risk reduction education; and discussion, through: medical providers and peer workers working together; evening outreach hours; and tools (e.g. syringe exchange, consistent services, transportation) (Shepard 2007). Outreach interventions were based on three theoretical frameworks – individual behaviour change, community and social networks, and relationship-building between provider and client (Shepard 2007, p27). Once a trusting relationship was established, services were provided in clients' rooms, or at the hospital or drop-in centre.

'Data mining' was the method used – secondary analysis of data already collected for other purposes – in this case, service utilisation patterns among participants engaged through outreach, compared with those engaged at the drop–in centre (Shepard 2007, p28). The hypothesis tested was that harm reduction outreach allows a hard–to reach population of PLHIV to access health care services.

Significant relationships between harm reduction services, medical care, housing placement and access to health care were identified. The authors concluded that their program theory was upheld by the data – harm reduction outreach, designed to reduce barriers to services and offering tools for better health, does increase access to medical care and provides strategies to reduce barriers. Limitations included that data mining excludes those outside the system, and does not include participants' perspectives.

The second study into PLHIV in SROs (Sohler et al 2009) examined gender disparities in HIV health care among the severely disadvantaged in the Bronx and Manhattan, New York City. Within a positivist paradigm, the researchers hypothesised that women are less likely to engage in optimal HIV care utilisation than men, and sought to explore reasons for disparities. They asked whether gender–based disparities in HIV related health care utilisation exist, and if so, whether they could be explained by participants' characteristics (education level, insurance status, drug use, housing) and/or their attitudes towards the health care system (such as trust in providers, engagement with workers, perceptions of access to care).

Methods used included interviews with a convenience sample of HIV-infected women and men living in 14 different single occupancy hotels in Manhattan and the Bronx in New York, between August 2004 and June 2005. Potential participants resided in an SRO, were HIV positive, at least 18 years of age, and Englishor Spanish-speaking. Interviews were administered using Audio-Computer-Assisted Self-Interviewing (ACASI) technology. Standardised questionnaire items included health status, drug and alcohol use, and socio-demographic information and use of HIV health services. Measures of attitudes to the health system and providers were included, encompassing perceptions of access, mistrust of health care system, trust in providers, engagement, and perceptions of personal treatment control.

Medical records were reviewed over the previous six month period and quantitative data extracted on HIV visits and CD4 counts. Analyses compared women and men on three outcome variables – use of primary HIV care services; use of emergency departments; and hospitalisations. Data was compared for women and men on demographic, socio-economic and behavioural characteristics.

Women were significantly less likely than men to engage in optimal HIV care. The observed disparity could not be explained, even after adjusting for further disadvantage (lower educational level, decreased likelihood of having health insurance). The researchers postulated that women's greater care–giving responsibilities may help explain the disparity – women may prioritise care of others over their own health care, although the study did not directly address this.

Findings suggest that strategies to improve access to HIV services need to consider possible gender differences and attempt to address them accordingly, and the study provides evidence for inequitable HIV care access for homeless women.

Another study explored factors associated with engaging marginalised PLHIV in care (Rumptz et al 2007). This study was situated within a constructivist paradigm, recognising that social determinants of health affect ability to engage in care. In some ways, however, the study can be described as 'cross-theoretical' (Bourgois 2002, p259), because it used strictly quantitative methods including epidemiological analysis, aligned with a positivist paradigm. This study provided a profile of PLHIV not fully engaged in HIV care, examined barriers to engagement and evaluated outreach interventions. It can be described as descriptive, evaluative or action research (Ovretveit 2002).

The populations studied were: sporadic users of HIV care; those receiving no care; and those who were engaged in care. The sample was recruited from 10 urban sites with outreach and advocacy interventions in place. Various outreach approaches existed, including mobile vans and street outreach.

Methods used were face-to-face questionnaire completion, with a purposive sample of 984 participants (at intake and 12-month follow up) and review of medical chart data.

Those who were not engaged in care, or only 'somewhat engaged' were more likely to report: drug use in the past 30 days; practical barriers to care (finding convenient appointment times, having no phone), health belief barriers to care ('faith will help', 'too healthy', 'no cure for HIV'); and to have a greater number of unmet needs than those engaged in care (Rumptz et al 2007, pS-35). The authors concluded that interventions addressing structural barriers and unmet needs, negative health beliefs and drug use are promising strategies to engage marginalised PLHIV in HIV care.

Another USA study examined characteristics of homeless HIV-positive outreach responders and their success in HIV primary care (Tommasello et al 2006). This study sits within the positivist paradigm.

The population accessed was homeless PLHIV with mental illness and substance use disorders in Baltimore, Maryland. The study was descriptive, utilising quantitative survey research methods to ascertain the intervention's effects on engagement with health services.

The intervention comprised intensive street outreach to homeless PLHIV with substance use and/or mental health disorders in soup kitchens, shelters, abandoned buildings shooting galleries and prisons. Workers built relationships with clients and provided items to meet immediate needs, whilst assessing for HIV risks, mental illness and drug use problems. Those who then came to the clinic received integrated health care, social services and case management.

Participants were assessed for changes to health measures over a 12-month period. Health surveys were conducted face-to-face (Medical Outcomes Study Health Survey and Patient Health Questionnaire) at baseline and scheduled for follow-up at 12 months, at 11 January 1998 and at 30 August 2001, with 110 clients enrolled.

Almost half of those enrolled in the study engaged with clinic services. At baseline, they had few service

connections, and the majority returned for follow-up interview 12 months later. Clients' need for services declined in almost every area; mental health and drug use showed significant improvement. The authors speculated that success was based on the development of reciprocal, caring relationships between outreach workers and clients, stating that 'in some cases, the relationship with the outreach worker may have been the most meaningful one in the client's life' (Tommasello et al 2006, p915). Generalisations cannot be made, due to potential sample bias and the lack of a comparison group.

A USA-based qualitative study examined the role of outreach in engaging and retaining PLHIV in medical care, from the perspective of PLHIV (Rajabiun et al 2007). This study belongs to the interpretivist paradigm (Sale et al 2002).

The population sampling frame was 'underserved' and 'hard to reach' PLHIV from seven sites participating in a funded Outreach Initiative. Seventy six participants were recruited purposively (Coyne 1997) for in–depth interviews from six cities, each site recruiting 8–16 participants. Those considered at high risk of disengagement or with limited access to health care were prioritised for inclusion.

Interviews were transcribed and analysed using QSR NVivo software and a grounded theory approach. Coding was undertaken and codes were collapsed into conceptual categories. The researchers sought to identify participants' history of health–seeking behaviour and experience within the health care system, barriers and facilitators to care, and the role of outreach interventions in assisting with engagement and retention in HIV care (Rajabiun et al 2007).

Data analysis indicated that study participants tended to 'cycle in and out of care' (Rajabiun et al 2007, pS-23). Factors identified as influencing engagement and retention in care included: level of acceptance of HIV status; ability to cope with stigma; substance use and mental health; health care provider relationships; presence of external support; and addressing systemic barriers. For instance, those who were not in care or unstable in care often denied their diagnosis or didn't see it as a priority. Those in care preferred to manage their HIV proactively. Participants who were not in care or unstable in care described experiences of discrimination and stigmatisation in healthcare, whereas those in care seemed to have coping strategies to deal with stigma, such as ignoring others' perceptions about HIV. Positive health care provider relationships were critical for those in care; in contrast, those not in care described negative experiences with providers.

Helpful outreach program strategies identified by PLHIV included: dispelling myths about HIV; improving knowledge; providing help and support with HIV care; building skills and ability to deal with HIV; reducing barriers to services (e.g. by organising transport, food, identification cards) and providing support networks. The important insight offered by this research was that engagement with HIV care services can be cyclical for homeless PLHIV.

A secondary publication drawing upon data derived from the same in-depth interview described above, examined the provider role in engagement (Mallinson et al 2007). Using a grounded theory approach, hence interpretivist in nature, narrative data from the interviews was analysed. Health care provider behaviours that clients perceived as validating, engaging and partnering enhanced and facilitated engagement and retention in care, whereas behaviours viewed as patronising or paternalistic hindered engagement and retention. Communication skills and empathy were also perceived as beneficial to engagement.

A Canadian study reported on a peer-driven intervention to improve access to HIV care and treatment for street-entrenched HIV-positive women, including transgender women (Deering et al 2009). The research design and methods used to evaluate the model indicate a strong commitment to positivism.

The model entailed four elements: weekly peer support meetings with the women; training for the women to become health advocates or 'buddies' for each other; a peer outreach service and a drop-in nursing service (Deering et al 2009, p604). Data collection consisted of three questionnaires – baseline intake assessment by a nurse, weekly questionnaire administered by the health advocates and a 3-monthly health questionnaire. Women were recruited through self-referral or through referral from other HIV providers, other health provider or friends in January through to August 2007 according to specific eligibility criteria.

Data from 20 participants were analysed, with trends of adherence to antiretroviral therapy by several behaviour variables known to affect adherence being examined (housing stability, drug use), exposure to the intervention and adherence, and the relationship between self–reported adherence and pharmacy recorded adherence. Viral load outcome measures (measures of HIV replication in the blood) were also recorded and analysed. Results indicated that the peer–driven intervention may have had a positive effect on adherence, since adherence either increased or remained the same for 75% of the women enrolled, and viral load measures decreased (compared with the year prior to enrolment). For higher risk women, the intervention may have been even more beneficial.

With a small sample size, statistical power was poor, but the authors reported the women involved appreciated the small group for peer support group meetings to promote cohesiveness and close bonds between them. Unfortunately, the purely quantitative approach precluded analysis of the women's own perspectives on the program which may have provided richer data with such a small group of participants.

Two Australian papers addressed issues of barriers to access to services for marginalised PLHIV within the context of service descriptions. The first utilised a case study-based approach, describing difficulties accessing housing, support, aged care, neuropsychological assessments and other services experienced by a Vietnamese injecting drug user with a criminal history, and a severe physical disability due to HIV-related cerebral toxoplasmosis (Crock et al 2011). The authors adopted a critical stance in articulating and describing structural barriers experienced by their client, and as such the research can be described as belonging to a critical paradigm (Willis 2007). These authors identified barriers to access based on covert, systematic discrimination and stigma, and emphasised the need for persistent advocacy, collaboration with the criminal justice system, a commitment to social justice, equity in health care, strong advocacy, with the case study as illustration, leading to stability and a positive outcome (Crock et al 2011). The case study approach enabled the authors to draw out in-depth personal data in narrative form and themes to be identified that helped to overcome barriers.

The second Australian paper described a community-based nursing role in caring for PLHIV that enhanced the care of PLHIV who have difficulty accessing health care. Located within a team of HIV specialist nurses in a not-for-profit community nursing organisation in Melbourne, Australia and operating within a flexible model of care, this new role complemented the existing program by providing HIV specialist nursing assessment and continuity of care to address the growing number of HIV clients with complex needs. This was primarily a descriptive study, within a post-positivist or constructivist paradigm. The roles described involve assertive outreach, care-coordination and inter-agency collaboration. Using case studies and interviews with specialist HIV nurses, the authors highlight the importance of a client and family-centred approach, participatory care planning and care coordination, cultural competence, and adherence to principles of social justice and equity.

Interestingly, these two papers which were principally descriptive in nature, provide insight into strategies used by community nurses to engage marginalised PLHIV in care, and how, in turn, the community nurses guide and assist PLHIV to gain confidence to navigate the wider health care system. 'HIV system navigation' has been proposed in other settings as a way to improve access to HIV care for marginalised PLHIV (Bradford

et al 2007, pS-49). This area requires further research as it is a little understood element of the HIV service system in Australia. It is noteworthy that a recent report documenting models of access and service delivery for PLHIV in the Australian setting omits discussion of specialist HIV community nursing services and their role in engaging PLHIV in care or in retaining people in care (Savage 2009).

CONCLUSION

This review identifies strategies described and evaluated in the social science literature which can improve access to HIV-care services for PLHIV who are homeless, at risk of homelessness or marginalised in other ways, partially answering the research questions. No literature was found that specifically addressed access to community nursing services for homeless PLHIV in the Australian setting, and very little internationally. Community-based nursing organisations can be well-placed and experienced in engaging groups such as these in care, indeed they have a long history of doing so (Archer 1904). This may mean that specific outreach interventions may not need to be developed in some settings, but rather, better use may be made of existing services that utilise assertive outreach models of care and co-location with other services (Bennett 2010). There is room to suggest that HIV-specific community nursing services could be better integrated with homelessness services to enhance access to care and link into the HIV medical and health system (see for example The Haymarket Foundation Inc 2011).

A broad range of quantitative and qualitative methods was used in the papers reviewed – survey research, in–depth interviews, case studies, epidemiological, and descriptive and comparative statistics, with most using quantitative methods. Many studies, although clearly social science, were situated in positivist paradigms, with an emphasis on measurement, quantification and statistical analysis of potential factors affecting engagement and retention in HIV care. Qualitative work including the use of in–depth interviewing and case studies provide additional insights into clients' and staff's perspectives into the research questions.

Assertive outreach (versus drop-in), harm reduction outreach, peer-driven outreach, case management, and interpersonal relationships between health workers and homeless PLHIV were significant factors that resulted in better engagement, improvement in access to and retention in HIV care. Reductions in drug use, structural barriers and number of unmet needs were all associated with engagement with services. Homeless PLHIV identified practices such as dispelling myths about HIV, improving knowledge, providing help and support with HIV care, building skills, providing practical support, and developing relationships as helpful to engagement. They appreciated validating and partnering relationships, and found patronising attitudes unhelpful. Philosophical and ethical approaches that focus on equity, social justice and structural advocacy provide promising but limited evidence for improved access to HIV care and other services. The establishment of HIV-specific roles within existing community nursing services can help to improve access to services for this group. The role of stigma and discrimination in deterring homeless PLHIV from accessing care was raised in all studies reviewed.

Barriers to access to services for homeless PLHIV have been identified in the literature. Poverty, negative past experiences, health beliefs (denial of HIV), recent drug use, mental health problems, drug use, were confirmed in this literature review. Experiences of HIV-related stigma and discrimination within the health care system compounded these issues for participants in some studies reviewed (Crock et al 2011, Rajabiun et al 2007). Some women with HIV including transgender women, may experience even poorer access to HIV care (Sohler et al 2009).

The broad range of methods described in this review provide insights into strategies to enhance and improve access to and engagement in HIV care. Further qualitative research into the complex issues faced by homeless

PLHIV requiring care could provide deeper knowledge of barriers they confront, and strategies that may promote and enhance their ability to access care. The absence of specific research into engagement with HIV specialist community nursing services demands further exploration.

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