

# Peer Support Models for People With a History of Injecting Drug Use Undertaking Assessment and Treatment for Hepatitis C Virus Infection

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People who inject drugs (PWID) are the group most affected by HCV; however, treatment uptake has been low. Engagement between PWID and healthcare workers has been characterized by mistrust and discrimination. Peer support for HCV is one way to overcome these barriers. Peer support models for chronic disease management have been successfully applied for other diseases. HCV peer support models have been implemented in various settings, but those that include opioid substitution treatment have been more common. Most models have been either service generated (provider led) or community controlled (peer led). Peer support models have been implemented successfully, with a range of outcomes including increased treatment knowledge and uptake and improved service provision. Genuine partnerships between peers and services were common across models and led to positive transformations for both clients and services. Further investigation of peer support for HCV treatment and its impact on both individuals and services is recommended.

**Keywords.** PWID; HCV; opiate substitution; drug users; people who use drugs.

In most developed nations, the burden of hepatitis C virus (HCV) infection is borne by people with a history of injecting drug use. Around 50% of existing cases and up to 90% of new cases are attributable to injecting drug use [1], while the prevalence of HCV among people who inject drugs (PWID) ranges from 65% to 90% [2]. Early advances in HCV treatment were achieved by replacing interferon monotherapy with combination pegylated interferon and ribavirin therapy. More recently, the development of direct-acting antiviral therapies with improved tolerability and efficacy have given the treatment sector reason for further optimism [3].

Among PWID, HCV treatment uptake remains relatively low with patient-, physician-, and structural-

related factors contributing to the low uptake [4]. Factors include patient mistrust [5] of the medical system; patients often find the system to be discriminatory or impenetrable [6]. While the treatment adherence and response to therapy of this patient group has been demonstrated as acceptable [7], some health workers still question the adherence capacities of PWID [8].

There is strong stigma associated with HCV, largely due to its link to injecting drug use and the illegality of drug use [9]. Stigma and discrimination are still unacceptably common within the healthcare sector [9, 10]. Healthcare workers are often either not aware of their discrimination or do not see their practice as discriminatory [11]. Both real and perceived discrimination impact greatly the assessment and treatment engagements [11] and can be closely linked to fear of disclosure of HCV status, as it implies drug use [12].

Peer support has been successfully implemented for people needing chronic disease management, including heart disease [13], diabetes [14], cancer [15], and human immunodeficiency virus (HIV) infection [16]. In the field of HCV, few papers have been published

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detailing HCV peer support models. To date, the focus has been on delivery models alongside drug treatment and harm-reduction services. The provision of opioid substitution therapy (OST) is a consistent feature of the settings discussed here. The current review summarizes peer support models that have been successful in enhancing assessment and treatment of HCV infection among PWID.

## PEER SUPPORT FOR HCV ASSESSMENT AND TREATMENT

Peer support models investigated to date can be grouped into 2 categories: community controlled and service generated.

Community-controlled peer support models have generally been implemented by peer-based drug user organizations in partnership with local service providers [17–20]. In Australia, these organizations have had a formal role in representing those most affected by HCV and feature strongly in these models. As will be discussed, these models are largely one-on-one support models based around OST clinics in which peer support workers (PSWs) offer detailed and ongoing support through the journey of HCV assessment and treatment. These models are completely controlled and implemented by the affected community through drug user organizations and are grass-roots community responses.

An early proponent of HCV peer support was the Organization to Achieve Solutions in Substance-Abuse (OASIS) clinic in Oakland, California [21]. This model—the OASIS model as we will refer to it—is service generated and peer supported. This type of model is conceived by the service or health center and uses peer groups of people considering or undergoing HCV treatment. These individuals are recruited and supported by the service itself. Group sessions are sometimes based around the existing structures and frameworks of self-help groups [21–25]. Key components of the model are outlined in the section “Service-Generated Models” below.

Peer support models are a valid feature of HCV assessment and treatment. Supporting communities of people who inject drugs to be involved in the delivery of peer-based support programs is important. Well-designed research is required to gain further understanding of the complexities of this type of model both in the context of OST delivery and in other settings. Recent work shows that HCV treatment peer support that is offered outside of drug treatment programs can also be viable [24]. Models that emphasize community self-determination should be further studied and implemented.

## SERVICE-GENERATED MODELS

Service-generated models in Oakland [21], Vancouver, Canada [23], and New York [25] share a number of common

characteristics. While all sites offer OST, only the New York site is primarily an OST clinic [25]. The models used at these sites share key elements with the biopsychosocial approach to substance use reduction or abstinence. This makes the approach familiar to those who have been involved in substance use treatment [21]. These approaches include self-help groups, peer interventions, and therapeutic communities. These elements of substance use treatment were “instinctively incorporated” by Sylvestre et al in design of the model used at OASIS [21].

## Key Components

In these models the self-help group cofacilitation by peers and service workers or researchers was central. In all models reviewed, large numbers of clients need to be engaged. Clients who completed treatment were engaged by the service to cofacilitate groups, and themes of self-transformation and telling of one’s story are core to the group [21, 23, 25, 26]. Group leaders use the Socratic approach to deliver information, with questions being used to allow the participants to come up with answers rather than straight delivery of information. Peer educators are crucial to the process; although the medical system has information, many peers distrust that system [26]. When the groups meet [21, 23, 25, 26], medical treatment including HCV assessment occurs concurrently, and participants may be called out of the group to access medical care if they have requested it.

## Training and Support

All sites incorporate training and mentorship [21, 23, 25, 26]. The initiative in New York outlines a comprehensive training package developed over many years of delivery [25]. At this site the peer educator’s roles are clear, and these are similar across the sites. They include recruitment of new patients, cofacilitation of biweekly HCV support and education groups, cofacilitation of weekly HCV group treatment sessions, patient escort to off-site procedures, development and implementation of peer-led HCV education, and participation in HCV advocacy activities. Supervision of peer educators is also outlined as crucial. There are weekly group sessions and individual meetings. This encourages reflective practice and review [25].

## Outcomes

These models engage large numbers of clients with many members of the client group being referred to HCV assessment and treatment. In 2007, OASIS had tested 3500 people for HCV infection and treated several hundred people [21]. The application of the OASIS model in Vancouver also led to large

numbers of people assessed and treated for HCV infection, with 204 participants accepting referral to the HCV support group. Of these, 53% were assessed for HCV and of these 13% had initiated or completed treatment before attending the support group; treatment was deferred in 25%; 10% were under evaluation; and 52% initiated treatment [23]. The Vancouver model also showed that attendees' lives improved in other areas including nutrition and health. Along with assessment and uptake, the potential for transformation both by the peers and the educator is highly emphasized. Peer HCV educators involved in the OASIS model speak strongly of the change in themselves and their peers through the processes [26]. The peer educator' role in this model can be practical and focuses on modeling positive behaviors [25, 26]. All models demonstrate that peer support can be an effective strategy for increasing HCV assessment and treatment uptake.

## COMMUNITY-CONTROLLED MODELS

In most developed nations, the primary community affected by HCV infection is people who inject or have a history of injecting drugs. In Australia, national and regional drug user organizations have a mandate to represent these communities and draw their staff and membership from the affected community. Community-controlled support models have largely arisen from work in Australia [17–20]. Two models run by NSW (New South Wales) Users & AIDS Association (NUAA) and one by Harm Reduction Victoria (formerly VivAIDS) are discussed here. NUAA is a New South Wales–based organization, while Harm Reduction Victoria is the Victoria state–based user organization. In these states the drug user organizations are funded to undertake peer education and support for people with a history of injecting drug use. A clear priority is working on HCV prevention and assessment as well as treatment support and advocacy. While the models to be discussed were generated by the affected community, it is clear that partnerships across the sector are crucial [17–20].

### OST Paradigm

The peer support models run by NUAA were based in specialized OST clinics. A short summary of the OST context is useful. It is often the case that the environment in which OST is delivered in NSW is highly regulated and other healthcare services are not usually offered, unlike the North American clinics such as OASIS, which offer a range of services for drug users. This intensive regulation is potentially problematic for the delivery of HCV treatment programs because the relationships between many OST clients and their clinic are not optimal and they have the potential to clash with the therapeutic needs of successful HCV treatment [6, 26]. Early evaluations of 1 HCV peer support site show that some OST clinic staff

doubt the suitability of OST clinics for delivering HCV treatment [26], given that OST clinics are often guilty of systemic and structural discrimination [6, 9, 26]. This discrimination is sometimes invisible to staff and clients alike but highly visible to clients [26]. In Australia, there is a mix of private fee-based clinics and public free clinics. The models run by NUAA were offered in each clinic setting.

## Key Components

In partnership with the University of New South Wales, as part of a large study to assess HCV treatment and uptake among PWID in the OST setting, NUAA developed 2 community-controlled models of care in Sydney and Newcastle, Australia [18–20]. The Harm Reduction Victoria (HRV) Healthy Liver Campaign in Melbourne, Australia, was developed in partnership with a primary health center [17].

The models consist of peer support workers (PSWs) closely supporting individuals through one-on-one support during HCV assessment and treatment. PSWs were members of a multidisciplinary team and facilitated referrals and recruitment into treatment and aimed to enhance treatment adherence and support [17]. The PSWs roles vary according to service models and restrictions, but they all provide support during assessment and treatment and provide a peer perspective to staff and a mediating role to service users [17–20]. The NUAA models developed as part of the Enhancing Treatment of Hepatitis C in Opiate Substitution Settings (ETHOS) Study differ in the nature of the peer relationship between PSWs and service users. At the regional site, which is a free public clinic, the PSW is not a patient of the clinic and is regarded as a service team member who assists in supporting access to blood tests and clinical services. This is very similar to the HRV HLC model. At the metropolitan private clinic, which is part of the ETHOS Study, clients of the service are employed as PSWs, and this affects the role they are free to undertake. The clinical support that is provided in the regional setting is not offered due to constraints on service clients' freedom of movement in the clinic. NUAA PSWs operate from the clinic's waiting area, where people queue to receive pharmacotherapy. Here, the PSWs undertake information sessions, recruitment into the cohort study, health promotions, and a range of activities around HCV assessment and treatment [20].

### Training and Support

The PSWs at all 3 models were employed, trained, and supervised by the local drug user organization. At the site where the PSWs were also clients of the service, NUAA ensured 2 PSWs were always employed together to offer mutual peer support. The restrictions placed on these workers were greater than those for the PSWs at other sites, who had greater access and

were a part of a multidisciplinary team [20]. So, within the same project and with the same duties, the PSWs at 1 site were treated differently from those at the other site because they were clients of the service, despite the fact that this was the only real difference between the PSWs. Although the peers were paid workers, part of a supervised and managed research project, and highly valued by the external project, their status within the site was marginalized because they were, in the end, clients. It is interesting that the locus of control still sits squarely with the organization and its needs [20]. NUAA provided initial and ongoing training as well as supervision for the NUAA PSWs [20].

The following challenges arose for the peer worker model, including at times feeling lonely and isolated at the clinic as well as feeling challenged by being expected to share information that may have been detrimental to a person's OST, for example, disclosure of drug use [17]. At each site, evaluations have clearly shown that service users had strong relationships with the PSWs and that these relationships eased fears around HCV treatment and made participation more likely [17–20].

## Outcomes

The narrative of transformation is strong throughout the service-generated models; however, it relates solely to the client or PSW. One key difference with the outcomes of the community models of peer support is a degree of transformation on the part of service providers as well. While there is evidence of client transformations occurring through the ETHOS sites [19], the actual clinics changed noticeably over time. The peer support model was recognized to have transformed the services and subsequently the experiences of service users, particularly on the days at the HCV clinic. As one service user who was interviewed said, "I think this place has improved out of sight as far as the feeling, the vibe of the place," which is confirmed by a staff member who state, "the atmosphere changes [when the PSWs are present]. And everyone's in a good mood." Staff also credited the service for showing that they are interested in the clients' overall welfare and involved in the health of clients [19]. As one PSW put it after the service installed a TV and DVD player in the waiting room, "[clients] see [the clinic] giving something back and not just taking [dosing fees] all the time" [20].

The importance of this transformation is simply that people actually see the service as a place where they might access more than a daily dose. The PSWs were clearly seen as peers and as agents of change by service users. One PSW noted, "I like that we have our own peers. . . . For someone like me . . . instead of having a text book person there, I listen more [to PSWs] . . . because they've been there and done that . . . yet are still on the 'done . . . you know people might not be interested but it slowly sinks in. . . . And I just think it's a top idea as opposed to the

people who are dosing doing it" [19]. This identification with the PSWs was also made clear in the evaluation of the HLC model [17].

As with the HLC model, the ETHOS PSWs are supervised by the state drug user organization. This has been crucial, including in managing challenges. As an endeavor with a range of partners and stakeholders, communication is key to ensuring that everyone involved has the same understanding of the project, where it is going, and how to get there. True partnerships based around trust have grown between the peer workers, the services, NUAA, and the researchers, and these partnerships have made it possible to meet challenges honestly and quickly [20].

## DISCUSSION

Peer support for people with a history of injecting drug use undergoing HCV assessment and treatment offers a range of benefits for both the individuals and the services involved. While the 6 models reviewed are all nominally about peer support for people undertaking HCV assessment and treatment, any comparisons must be understood in the context of treatment and service delivery. The North American models are based in services that are community-based models and that are flexible and responsive services that work on the principles to reduce harm reduction [21–23]. The Australian models, on the other hand, are set in a highly regulated environment with inherent structural barriers [26].

The service-generated models have evolved in settings that are conducive to, or already offer, substance use support groups [21, 25]. It is clear there was meaningful peer involvement at all sites, but the parameters of the peer support models are set largely by the services. In the community-controlled models, peers set the parameters of these models, and in the context of these regulated environments, it is inevitable that these parameters may include service change.

In the community-controlled models the level of identification between peer workers and service users is very high [17]. This has the capacity to overcome the mistrust that many service users feel for OST services [19] and offers intensive support for people with multiple issues. Nevertheless, the peer workers at both the HLC and ETHOS sites were outsiders to the service, and their clear identification with service users could lead to feelings of isolation [17] as well as camaraderie [19]. The ETHOS site peer workers were treated differently, depending on their status as a client, the very quality that makes them a peer. Investigation of the impact of such issues should be undertaken.

The service-generated models were highly effective at managing large numbers of clients through the process [21] and are

well received by those who are ready for a sharing and group model approach [25]. Peer support phone-lines are common outside of HCV treatment. There are some examples within the sector, and their impact should be evaluated further also.

Peer support models are an effective approach both in terms of assessment and treatment uptake as well as in terms of individual and, sometimes, service transformation. Where there is resourced support, peers can independently plan and implement models of peer support as equal partners. Organizational barriers, particularly in highly regulated OST environments, must be diminished to allow these partnerships genuine equality.

In addition, peer-driven research and equitable involvement in research development should be further undertaken to ensure that the needs of the PSWs and peer organizations are better understood and that peer support models can be matched to service models effectively.

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