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Tensions in relation: How peer support is experienced and received in a hepatitis C treatment intervention

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ABSTRACT

Background: Peer support and involvement is recognised as a vital component of hepatitis C (HCV) treatment provision for marginalised populations, such as people who inject drugs (PWID). Developments in HCV treatments enable increased provision in community settings – expanding the possibilities for meaningful peer involvement in HCV treatment plans. To date, HCV peer support has generally been viewed as a positive intervention, with little critical reflection on the ways social structures, policies, health and drug services and social identity impact on how peer support is experienced and received.

Methods: We report on the qualitative component of a UK-based intervention designed to increase HCV diagnosis and treatment in primary care and drug treatment settings. Data were collected between 2014 and 2016. Pre-intervention, a total of 35 PWID clients took part in nine in-depth interviews and four focus groups. In addition, 22 drug services and intervention providers took part in two focus groups and nine interviews. Post-intervention, one focus group and eight interviews were conducted with 13 PWID clients, and four focus groups and ten interviews were conducted with 26 drug services and intervention providers. Our data generation and thematic analysis focused on the peer education and buddy support component of the intervention.

Results: Participants had common expectations of the peer role (to 'just be there') and its occupants' attributes (empathy, trustworthy, etc.). However, in practice, peers faced constraints on realising these expectations. A 'recovery' dominated drug treatment ethos in the UK appeared to influence the selection of 'recovery champions' as peers for the intervention. This created tensions in relations with clients, particularly when risk-adverse discourses were internalised by the peers. Peers were poorly integrated and supported within the service, affecting opportunities to relate and build trust with clients. Thus, the scope for peer support to impact on the nature and extent of clients' testing and treatment for HCV was limited.

Conclusion: The efficacy of peer involvement can be constrained by organisational structures and boundaries – especially regarding who is deemed to be 'a peer'. Peer programmes take time and care to implement and weave into wider recovery and harm reduction frameworks.

Introduction

Peer support and involvement is recognised as a vital component of hepatitis C (HCV) treatment provision for marginalised populations, such as people who inject drugs (PWID). In recent times, the possibilities for meaningful peer involvement in HCV treatment plans have increased with the development of interferon-free direct-acting antiviral therapies (DAAs). These relatively simple, tolerable and highly effective treatments enhance the opportunities for provision in community settings, such as drug treatment centres (Alavi et al., 2013; Harris Jr., Arnsten & Litwin, 2010). In the context of simplified drug regimens, barriers to testing and treatment uptake are still likely, particularly if hospital appointments for initial assessments are involved. A wealth of qualitative research illustrates barriers to tertiary care services for PWID due to accessibility issues, historical discrimination and/or anticipated stigma (Harris, Rhodes, & Martin, 2013; Swan et al., 2010). Here peer accompaniment has the potential to make an important difference. Indeed, peers could be vitally important throughout the cascade of care, especially regarding case-finding and challenging the ubiquity of messages held by PWID regarding the difficulty of traditional HCV treatment (Whiteley, Whittaker, Elliott, & Cunningham-Burley, 2016). Peer support may also be important to facilitate treatment adherence and post-treatment

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prevention support to avoid reinfection. If peers are to be involved in such support provision, it is important that their views and experiences are taken into consideration in the development, oversight and implementation of new initiatives.

To date, HCV peer support has generally been viewed as a positive intervention. The involvement of peers in HCV testing and treatment provision can: help reduce PWID fears of testing and treatment; improve PWID HCV knowledge and engagement through the care cascade; improve healthcare provider appreciation of PWID needs; and challenge structural barriers (Crawford & Bath, 2013; Harris, McDonald, & Rhodes, 2014; Norman et al., 2008; Roose, Cockerham-Colas, Soloway, Batchelder, & Litwin, 2014). At the same time as providing a generally positive valuation, researchers often reify and package peer support such that its implementation can seem somewhat fixed and straightforward, irrespective of social and service contexts or the concerns of PWID and those who take on peer roles. In this respect, HCV peer functions tend to reduce to a toolkit comprising the co-facilitation of treatment, chaperoning patients to hospital appointments and engaging in educative activities within and outside of drug service settings (Crawford & Bath, 2013; Norman et al., 2008; Roose et al., 2014; Treloar et al., 2015).

Much of this previous research has been done with little critical reflection on how social structures, policies, health and drug services and social identity impact on the ways in which peer support is experienced and received (Treloar, Rance, Laybutt, & Crawford, 2011). A recent systematic review (MacLellan, Surey, Abubakar, & Stagg, 2015) of peer support workers' experiences across all health contexts found only one study reporting on the perspectives of HCV peer workers (Norman et al., 2008) and it appears only one study has been published since (Treloar et al., 2015); both originate from Australia. HCV peers' experiences of their roles, especially in the UK context, remain relatively unexplored. Moreover, little is known about drug treatment clients' and providers' perspectives on and experiences of HCV peer support. The aim of this study, therefore, was to conduct a critical qualitative exploration of HCV peer support implementation in drug treatment settings from multiple perspectives in order to inform the successful scale-up of HCV treatment provision for marginalised populations in the DAA era.

Methods

Setting & rationale

This paper reports findings from the qualitative component of a complex intervention study aiming to increase HCV diagnosis and treatment in primary care and drug treatment settings (HepCATT: Hepatitis C Awareness Through to Treatment). Two interventions were developed, implemented and evaluated – one for primary care services, the other for drug treatment services. We report on the intervention implemented in three UK drug treatment centres. These centres serve people with drug and alcohol addictions and are funded by a range of sources. Briefly, the year-long intervention comprised: a HCV nurse facilitator on-site for two days a week; on-site HCV testing (ad hoc and planned sessions); streamlined treatment pathways; a peer education and buddy system; and drug service provider education. The intervention coincided with the introduction of DAA treatments in the UK. In this study, clients were variously prescribed pegylated interferon and ribavirin, a combination of pegylated interferon and ribavirin with DAAs, or purely DAA treatment, depending upon their genotype and the policies of the local healthcare authorities, which were in development during the intervention.

A qualitative assessment was conducted pre- and post-intervention, which included interviews and focus groups at two of the three services sites. The principle aim of this was to inform and assess the intervention, with a focus on the peer education and buddy support component. In each site, the peer support system was set up by the Hepatitis C Trust, a UK charity, which gave initial training and on-going support to newly recruited peers and buddies, as well as drug service staff. The set-up of this system therefore escaped Crawford and Bath's (2013) previous categorisation of 'community controlled' (implemented by peer based drug user organisations in partnership with local service providers) and 'service generated' (initiated and managed by health/drug services) models. Though it shared elements of both categories, the HepCATT model occupied a nebulous middle ground between the two.

Sample

A purposive sample of PWID clients of the two drug treatment service sites was recruited via on-site drug treatment staff both pre- and post-intervention. The pre-intervention client sample was split into those who had previously tested positive for HCV but not entered treatment and those who had never had a test for HCV. Drug service staff (key workers, nurses, team leaders) who came into contact with PWID clients and intervention providers (nurse facilitators, buddies and peers) were also recruited. Post-intervention, the client sample was divided into those who had 'engaged' with the intervention (defined as attending an appointment at the hospital to discuss results and treatment options and deciding whether to go through with treatment or not) and those who had 'not engaged' (i.e. not been tested or not transitioned to discussing test results at the hospital during the intervention). Recruitment problems meant significantly fewer clients participated post-intervention, and there were not enough participants to form more than one focus group. The drug services found it incredibly difficult to recruit 'non-engagers' at both sites. At the outset of the study, the idea was to recruit some people post-intervention who had also been interviewed pre-intervention. This was only possible in three cases due to clients disengaging from the drug service during the intervention, and the unavailability of clients to take part in the study post-intervention.

Likewise, drug service staff who had experience of the intervention in some way (e.g. referring clients, receiving education, overseeing the peer system) and intervention providers (nurse facilitators, buddies and peers) were also recruited. Data collection took place between 2014 and 2016. All participants read an information sheet about the study and had opportunities to ask questions before giving their informed consent to participate. Ethical approval was obtained from the LSHTM Research Ethics Committee [8935] and the NHS Health Research Authority's National Research Ethics Service [IS/EM/0062].

Interviews, focus groups & observations

Participants were invited to take part in a one-to-one interview or focus group and they made the decision as to which one they preferred. Pre-intervention, a total of 35 PWID clients took part in nine in-depth interviews and four focus groups. In addition, 22 drug services and intervention providers took part in two focus groups and nine interviews. Post-intervention, one focus group and eight interviews were conducted with 13 PWID clients, and four focus groups and ten interviews were conducted with 26 drug services and intervention providers. In total there were 96 participants, 10 of whom from all sub-samples took part both pre- and post-intervention (see Table 1) Data collection stopped when thematic saturation had been reached. Interviews lasted between 30–75 min and focus groups lasted between 1–2.5 h. These took place in private rooms at the drug treatment services. All interviews were conducted one-to-one. They were especially useful for clients who did not want to discuss their experiences,