

From peer-based to peer-led: redefining the role of peers across the hepatitis C care pathway: HepCare Europe

Julian Surey^{1–3*}, Dee Menezes⁴, Marie Francis^{1,2}, John Gibbons^{2,5}, Binta Sultan¹, Ala Miah⁵, Ibrahim Abubakar¹ and Alistair Story^{2,6}

¹Institute of Global Health, University College London, London, UK; ²Find and Treat, University College London Hospitals NHS Trust, London, UK; ³Universidad Autónoma de Madrid, Madrid, Spain; ⁴Institute of Health Informatics, University College London, London, UK; ⁵Groundswell, London, UK; ⁶Collaborative Centre for Inclusion Health, UCL, London, UK

*Corresponding author. E-mail: j.surey@ucl.ac.uk

Background: HCV infection disproportionately affects underserved populations such as homeless individuals, people who inject drugs and prison populations. Peer advocacy can enable active engagement with healthcare services and increase the likelihood of favourable treatment outcomes.

Objectives: This observational study aims to assess the burden of disease in these underserved populations and describe the role of peer support in linking these individuals to specialist treatment services.

Methods: Services were identified if they had a high proportion of individuals with risk factors for HCV, such as injecting drug use or homelessness. Individuals were screened for HCV using point-of-care tests and a portable FibroScan. All positive cases received peer support for linkage to specialist care. Information was gathered on risk factors, demographics and follow-up information regarding linkage to care and treatment outcomes.

Results: A total of 461 individuals were screened, of which 197 (42.7%) were chronically infected with HCV. Referral was made to secondary care for 176 (89.3%) and all received peer support, with 104 (52.8%) individuals engaged with treatment centres. Of these, 89 (85.6%) started treatment and 76 (85.4%) had a favourable outcome. Factors associated with not being approved for treatment were recent homelessness, younger age and current crack cocaine injecting.

Conclusions: Highly trained peer support workers working as part of a specialist outreach clinical team help to identify a high proportion of individuals exposed to HCV, achieve high rates of engagement with treatment services and maintain high rates of treatment success amongst a population with complex needs.

Introduction

HCV infection is a major cause of chronic liver disease and death globally.¹ In the UK, HCV infection occurs primarily through injecting drug use.² Chronically infected people are at risk of progressive liver disease characterized by hepatocellular inflammation, hepatic fibrosis, cirrhosis and hepatocellular carcinoma.³

In the UK and many other countries HCV disproportionately affects underserved populations such as homeless individuals, people who inject drugs (PWID) and prison populations. New drug therapies, such as protease and polymerase inhibitors, called direct-acting antivirals (DAAs), have been shown to be well tolerated and highly effective, meaning that HCV elimination is being considered as a realistic possibility.⁴ However, underserved populations (whilst most at risk of HCV) encounter the biggest challenges in terms of testing, linkage to care and treatment.⁵

A high prevalence of 13% chronic HCV infection has been found previously among homeless people opportunistically screened at residential hostels and day centres across London.⁶ Data from the HALT Hepatitis Study showed that 35% of HCV antibody-positive recruits were homeless at enrolment and that over 50% of HCV-infected patients knew of their status but had disengaged from treatment services.⁷ This population therefore includes a high number of undiagnosed cases and previously known HCV-positive cases who are not accessing treatment services.

Strategies to improve HCV case detection and management can draw from emerging evidence from TB management. TB is a disease that affects a similar group of individuals in whom community models have been proposed and adopted for some time.⁸ These outreach models of care focus on active case finding and treatment support in vulnerable groups and have been shown to be cost-effective in high-income countries.⁹

Peer support has emerged as a potentially useful tool to improve patient outcomes and can be used as a mechanism to enable active engagement with healthcare among underserved populations. Peers, with their lived experience of a lifestyle or condition, can share similar experiences or characteristics with the target intervention group, giving them a connection that enables them to support others facing similar challenges.¹⁰

The use of peer support models in healthcare has been used particularly in mental health services, where peer support workers (PSWs) serve to improve engagement with healthcare and positive health outcomes among their clients.^{11,12} Peers will typically be recruited from within the client pool of a service and are given some simple training for the role of offering support to other individuals to aid their journey to recovery.¹³ This could entail helping people with attendance at appointments, medication adherence or healthy lifestyle changes, to achieve an optimal outcome that aids their recovery. Successful examples have been seen in chronic^{14,15} and infectious diseases¹⁶⁻¹⁸ and people who misuse substances.¹⁹

In HCV, peers have been used in a number of roles aiding individuals to engage with treatment and qualitative and observational studies have shown a breadth of strategies in the cascade of care with mixed results.¹⁹⁻²⁷ One randomized controlled trial (RCT) has shown a positive effect of peer support in engagement with services compared with standard of care; however, this did not include treatment uptake or completion outcomes.⁷

HepCare is co-funded by the European Commission and aims to develop models of care that link primary, secondary, outreach and community care and treatment for at-risk populations across four EU sites (Ireland, UK, Spain and Romania). The London site leads on a work package that uses specialist outreach interventions based on peer support in the community to increase awareness of the risk of HCV and the importance of testing and to provide linkage to care and treatment support for vulnerable groups. This observational study assessed the burden of disease in an underserved population and describes the role of peer support in linking these individuals to specialist treatment services.

Methods

Ethics and governance

Research ethics approval was obtained from the North West – Haydock Research Ethics Committee (17/NW/0417). Governance and oversight for the study were provided through the overall governance structure of the HepCare Europe Project. An International Advisory Board (comprising clinicians, academics, researchers and representatives of EU regulatory bodies and service user organizations) provided external oversight for the project. A Project Steering Group comprising Work Package and Site leaders provided internal oversight. Finally, site-specific teams were established to execute the project at each site.

Study design and setting

The HepCare team recruited participants nested within the Find&Treat Mobile Health Unit (MHU), University College London Hospital (UCLH) NHS Trust, which provides health screening for homeless individuals across London using community interventions and specialist outreach workers. In collaboration with the homeless peer advocacy organization Groundswell, a peer-led community outreach service was developed to test individuals at risk of HCV, link them to specialist care and provide treatment support.

Groundswell has developed a Homeless Health Peer Advocacy (HHPA) service that uses PSWs to accompany and support individuals to healthcare appointments. Peers were selected from an experienced pool of PSWs from Groundswell who expressed an interest in working with the project and who had a level of competency commensurate with the outreach role. They were given additional training in HCV awareness, testing and the use of a FibroScan for liver fibrosis by the outreach team and worked alongside the outreach nurses until they were assessed as having sufficient competency. Peers were also to take individuals to clinical appointments as well as monitor treatment adherence whilst working under the clinical supervision of a nurse specialist.

Sites and patient identification

Sites were identified if they were deemed to have a high proportion of individuals with risk factors for HCV such as injecting drug use, and included homeless hostels, day centres and drug treatment services. Inclusion criteria were being over 16 years of age, a willingness and ability to provide signed informed consent and being from an underserved population in the community. This was defined as groups whose social circumstances make it difficult to access services and could include people who are homeless, people who misuse substances and people exposed to the prison system. Prior to screening, sites were visited by a member of the team to speak to staff and service users. Posters and leaflets were also left with information about what activities were available on the day.

Patient recruitment

Individuals were approached by a member of the clinical team and, following provision of informed consent and a conversation regarding risk factors, were offered HCV testing. Initially individuals were tested using the OraQuick HCV rapid antibody point-of-care mouth swab, which gives a result in 20 min. Those positive for HCV antibody were then tested for chronic infection using either dried blood spot tests or venous sampling for HCV RNA. Results would take approximately 7 days. Those who reported previously having tested antibody or RNA positive were either re-tested for HCV RNA, or were confirmed as being chronically infected via healthcare records (retrospectively). Those testing positive, reporting a previous positive result or with risk factors for liver disease were offered a liver assessment using a portable FibroScan, which uses transient elastography to assess liver fibrosis.

Peer support and linkage to care

All those chronically infected were followed up by a PSW who would meet the patient after the test result to explain the care pathway. All were to be referred directly to specialist treatment services by a nurse specialist and clinical appointments were made. PSWs would accompany individuals to hepatology and related healthcare appointments and cover associated travel costs. Other facilitators provided would be a drink and food whilst waiting as well as mobile phone top-up credit. To support individuals through treatment, PSWs would keep in contact by regular phone calls or face-to-face meetings or supervising medication by directly observing therapy (DOT).

Data collection

Information was gathered on risk factors and demographic information at screening as part of routine patient care. Follow-up information regarding linkage to care and treatment outcomes was gathered by the contacting patients and support services by a member of the clinical team. All patient data were entered into a patient management system database and an anonymized extract of the data was analysed using STATA 15.1. Summary data were calculated and logistic regression was used to explore the associations with achieving linkage to care and

a successful treatment outcome such as completing treatment with sustained virological response (SVR).

Results

Population characteristics

A total of 461 individuals were screened between September 2016 and May 2018 across 63 sites in London, such as drug and alcohol services, homeless day centres and homeless hostels, over 109 sessions. The majority (78.7%) were male, the median age was 45.7 years (IQR 39–52), they were mostly UK born (76.6%) and white ethnicity was the most common (88.8%). Over half (59.9%) had been recently homeless, defined as rough sleeping or in a hostel within the past 12 months. For full results see Table 1.

Many reported that they had had a previous HCV antibody test (356, 77.2%), with 255 (55.3%) individuals reporting a previous positive test. Most of individuals with a positive test (198, 77.6%) stated that they were disengaged from treatment services. In total 266 (57.7%) individuals were found to have been exposed to HCV. The vast majority (92.5%) had a history of injecting drug use with 33.8% currently injecting and 73% currently on opiate substitution therapy (OST). Problem alcohol use was high, with over a third reporting daily alcohol intake with >50 units each week and nearly a quarter (23.7%) with daily consumption and more than 100 units each week.

Cascade of care

Following HCV RNA testing a total of 197 individuals (42.7% of the total population) were identified as being HCV RNA positive and disengaged from treatment services. Referral was made to secondary care for 176 (89.3%) individuals, 14 (7.1%) were lost to follow-up after RNA testing, 4 (2%) were in progress at the time of data collection and 3 (1.5%) were not required as they were already being treated. All received varying degrees of peer support, with 104 (52.8%) individuals sufficiently engaged with treatment centres to be approved for treatment. This would typically require at least two appointments and completion of pre-treatment investigations such as ultrasound scanning and baseline blood tests. Of those approved, 89 started treatment and of these 20 (22.5%) had completed treatment with SVR, 43 (41.3%) completed with SVR results pending and 13 (12.5%) were still on treatment (Table 2). This makes a total of 76 (85.4%) with a favourable outcome following treatment initiation, or 38.6% of all those identified with HCV (Figure 1).

Risk factors associated with approval for treatment

Variables thought to affect the likelihood of being approved for treatment were investigated using univariate logistic regression (Table 3). Increasing age was associated with being more likely to be approved for treatment (OR 1.04, CI 1.0–1.08, $P=0.01$). Those with a recent history of homelessness, defined as rough sleeping or living in a homeless hostel in the previous year, were less likely to be approved (OR 0.53, CI 0.3–0.93, $P=0.03$), as were those currently injecting crack cocaine (OR 0.49, CI 0.25–0.92, $P=0.03$).

Table 1. Population characteristics: overall and of those with and without anti-HCV antibodies

Characteristic	Overall		Anti-HCV antibody status			
	no.	%	positive		negative	
	no.	%	no.	%	no.	%
Total population	461	–	195	42.3	266	57.7
male	363	78.7	155	79.5	208	78.2
female	98	21.3	40	20.5	58	21.8
Age category (years)						
16–25	13	2.8	10	5.1	3	1.1
26–35	61	13.2	29	14.9	32	12.0
36–45	160	34.7	63	32.3	97	36.5
46–55	157	34.1	61	31.3	96	36.1
56–65	64	13.9	28	14.4	36	13.5
66–75	3	0.7	1	0.5	2	0.8
missing	3	0.7	3	1.5	0	0.0
UK born						
no	108	23.4	54	27.7	54	20.3
yes	353	76.6	141	72.3	212	79.7
Homeless recently						
no	185	40.1	63	32.3	122	45.9
yes	276	59.9	132	67.7	144	54.1
OST currently						
no	194	42.1	123	63.1	71	26.7
yes	267	57.9	72	36.9	195	73.3
Ever injected drugs						
no	132	28.6	112	57.4	20	7.5
yes	329	71.4	83	42.6	246	92.5
Currently injecting drugs						
no	336	72.9	160	82.1	176	66.2
yes	125	27.1	35	18.0	90	33.8
Alcohol use						
>50 units per week						
no	306	66.4	136	69.7	170	63.9
yes	155	33.6	59	30.3	96	36.1
>100 units per week						
no	355	77.0	152	78.0	203	76.3
yes	106	23.0	43	22.1	63	23.7
Previous HCV antibody test						
no	75	16.3	71	29.3	4	1.8
yes	356	77.2	146	60.3	210	95.9
not sure	4	0.8	4	1.65	0	–
missing	26	5.6	21	8.7	5	2.3
FibroScan (kPa)						
F1	184	62.4	53	27.2	131	49.3
F2	44	14.9	7	3.59	37	13.91
F3	22	7.5	1	0.5	21	17.9
F4	45	15.3	5	2.6	40	15.0

^aThese are mean FibroScan values rather than percentages.

Discussion

This observational study in an underserved population at risk of HCV found a high level of peer-supported patient engagement, with over half (52.8%) of those screened and found to have chronic

HCV being approved for treatment and 38.6% having a favourable treatment outcome. The burden of disease was high, with 42.7% of people screened identified as being infected with HCV, and amongst these liver disease was high, over a quarter having severe liver fibrosis or cirrhosis. The outcomes in this underserved population compare favourably with the standard of care reported in the UK, where the cascade of care typically treats 5% of those with

HCV,²⁸ albeit from data in the pre-DAA era. It also outperforms a previous RCT amongst a similar population, which showed that 18% of those referred directly into care without peer support achieved engagement with services against 36.5% who did have peer support.⁷

Whilst the outcomes achieved were encouraging, nearly half of the individuals were not approved for treatment and loss to follow-up was still significant. Consequently, the HepCare team has instituted a policy of continuous open-ended care whereby individuals are given multiple opportunities to engage. If individuals proved uncontactable, PSWs would contact keyworkers and visit hostels to try to maintain engagement with the patient. If treatment was declined at that time, the decision would be respected and they would be re-contacted at a later date, in case they changed their mind. Further qualitative work is under way amongst this patient group to explore some of the reasons why they feel that treatment is not right for them at that time.

The PSWs used a range of strategies depending on the individual needs of the patient and on the personal relationship developed. Some would simply require referral and a telephone reminder about an appointment, while others would need intensive support both to facilitate the patient to attend and reassure prescribing services that the patient is sufficiently motivated to commence therapy.

There have been many models of peer support, from using peer support groups²⁴ to ‘buddy’-type interventions;²⁹ however, often the peer has a limited role on the periphery of a service.³⁰ Our model of having the peer central to the service, and using peers who are highly trained and can navigate a client from testing to treatment completion, may be a reason for the outcomes achieved here. Further qualitative work, which we have started, will explore these themes.

The success of peer interventions relies in part on the interpersonal relationship between the peer and service user. Qualitative studies have highlighted the importance of trust between peer and service user born out of a shared experience.²⁷ This is especially important with this client group as they are often stigmatized for

Table 2. The linkage to care cascade

Characteristic	Number of patients	Percentage
Total number HCV RNA positive	197	42.7
Referred to specialist care		
complete	176	89.3
in progress	18	9.1
not applicable	3	1.5
Outcomes post-referral		
engaged with services	147	74.6
attended specialist appointment	113	57.4
Total approved for treatment	104	52.8
Started treatment	89/104	85.6
on treatment	13	12.5
⊗ complete with SVR	20	19.2
⊗ complete with SVR pending	43	41.3
Total positive outcome	76/89	85.4
⊗ completed no SVR	2	1.9
⊗ pause (medical)	1	1.0
⊗ pause (social)	4	3.8
⊗ started: died (other cause)	2	1.9
⊗ started: died (HCV)	1	1.0
treatment abandoned	3	2.9
Total negative outcome	13/89	14.6
Outcome of all chronic HCV		
positive outcome	76/197	38.6
negative outcome	121/197	61.4

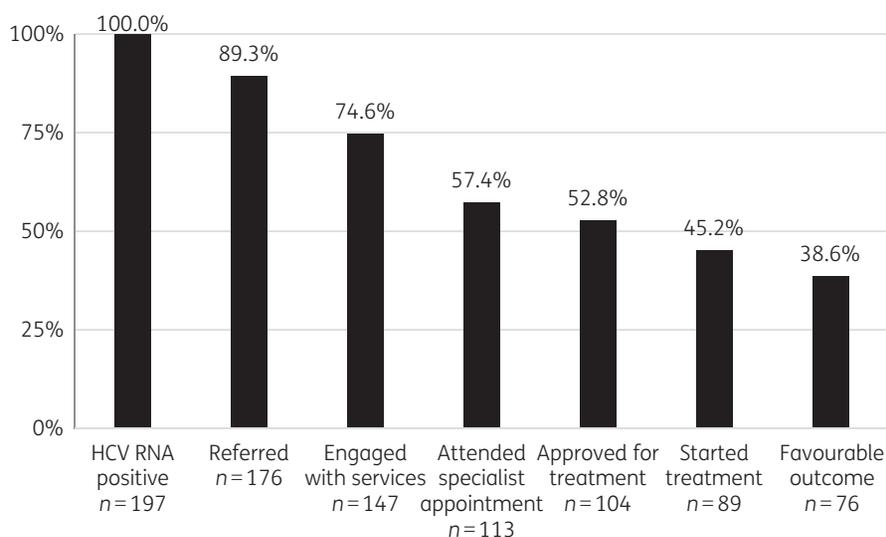


Figure 1. Cascade of care from testing positive to treatment outcome.

Table 3. Risk factors associated with approval for HCV treatment

Characteristic	Not approved (n=93)		Approved (n=104)		Logistic regression	
	no.	%	no.	%	OR	P value
Homeless	55	59.1	45	43.3	0.53	0.03
Age (years)	93	44.6 ^a	104	48.1 ^a	1.04	0.01
Injecting crack cocaine (current)	33	35.5	22	21.2	0.488	0.03
Current injecting (all drugs)	38	40.9	29	27.9	0.56	0.06
Problem alcohol use (>100 units)	27	29.0	18	17.3	0.512	0.05
UK born	77	82.8	76	73.1	0.564	0.10
Gender	73	78.5	86	82.7	-	0.46
OST (current)	65	69.9	79	76.0	-	0.34
OST (disengaged)	14	15.1	16	15.4	-	0.95

^aThese are mean ages (in years) rather than percentages.

their social situation and perceived behaviour, i.e. homelessness and substance use. Numerous studies have highlighted the difficulty for homeless people and PWID in accessing adequate healthcare, and so having someone with a similar lived experience to help them navigate through the system is a powerful tool in reducing health inequalities.³¹

The UK now has no restrictions on eligibility for HCV treatment based on fibrosis stage or injecting drug use; however, there are still many barriers to accessing care.^{32,33} There has been an increase in outreach activity in the community, such as in drug treatment centres,³⁴ but these often rely on an individual being engaged with services, for example OST. Those not on OST and injecting drugs are at higher risk of transmission of HCV and are less likely to be in contact with harm reduction and drug treatment services. This particular group, whilst small in our study, was no less likely to be approved for treatment, indicating that engagement with services can be achieved. Future work should aim to explore this in more detail using a mixed-methods approach to inform future elimination strategies.

The majority of patients had been tested previously, suggesting that there is still a large pool of people who are disengaged from treatment services. This pool of 'known positives' highlights the need for an enhanced case management approach that is better tailored to the complex social needs of the individual, such as is common in TB control.³⁵ Qualitative studies have shown a perceived lack of importance given to this disease by healthcare professionals, which is then taken on by the individual themselves and so acts as a disincentive to seek and adhere to treatment.³⁶

Underserved populations such as the homeless, people with problematic substance and alcohol use and imprisoned individuals are known to suffer extreme health inequities.³¹ Univariate analysis in this population indicated that homeless individuals, injecting drug use and younger age were all associated with being more likely to be approved for treatment, supporting this concept. These risk factors are common among those infected with HCV and so addressing these complex social needs is important in efforts to reduce the burden and morbidity in this population. This is why HCV treatment strategies may be more effective, both in terms of impact and in cost-effectiveness, by being designed in a

multidisciplinary manner. This could be a multidisciplinary community healthcare model, where multiple interventions can be simultaneously provided to an individual, who may have multiple risk factors, rather than a pathogen-specific model of disease elimination.

Peer support is considered a key priority in HCV elimination and it is perceived to be a low-cost intervention and to contribute to a more effective use of healthcare resources.^{27,37} A cost-effectiveness analysis of this intervention in comparison with current care pathways was carried out by the University of Bristol. Using the full list price for drug treatment it was found to be cost-effective at a willingness-to-pay threshold of £20000 per quality-adjusted life year (QALY) gained.³⁸ Furthermore, Ward *et al.*³⁸ found this intervention to be cost-saving at 45% of the UK list price for sofosbuvir and velpatasvir (£17539 per course). Future cost-effectiveness evaluation would be useful in assessing this peer model as part of a complex intervention for the multiple healthcare and social needs of underserved populations.

While it could be said that a limitation of this study is its observational study design and the lack of a comparator population, it was felt a comparator was no longer necessary as the aforementioned previous RCT already found peers to be beneficial in linkage to care.⁷ Rather, this study was intended to be a continuation of that work in exploring the care cascade of HCV and the peer-led model of care in this population. There were a number of patients who were not contactable following referral and it is possible that they were more likely to have a negative outcome. However, some of those who had approval or treatment dates pending may have likewise achieved a positive outcome following the end of data collection for this study. It is estimated that these two subgroups would balance each other out and would not significantly affect the results. The team relied on a small number of motivated, highly trained peers and so the rollout of this model may not achieve the same outcomes we found.

As part of knowledge and expertise sharing of the HepCare consortium, the development of peer networks has commenced in partner sites in Dublin, Seville and Bucharest. Peers have been trained in HCV awareness and are tasked with improving uptake in testing and improving linkage to care. It is hoped that future

work will utilize the peer-led model described here: i.e. that peers are highly trained, central to the clinical team and involved with all aspects of the cascade of care; and that others can replicate our results in achieving good outcomes in terms of treatment uptake and completion.

Conclusions

Highly trained PSWs working as part of a specialist outreach clinical team help to identify a high proportion of individuals exposed to HCV, achieve high rates of engagement with treatment services and maintain high rates of treatment success amongst a population with complex needs. Peers have a unique role in engaging with underserved populations and we have shown they can be successfully integrated into community interventions to improve case finding and treatment outcomes. Peers can also be a powerful resource to empower patients to access treatment, which is vital if we are to eliminate HCV as a public health concern. The rollout of peer interventions across other sites could be a valuable tool in reducing HCV prevalence and its eventual elimination.

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