

2021-12-03

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<http://hdl.handle.net/10026.1/18484>





10.1111/hex.13400

Health Expectations

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Barriers and facilitators to hepatitis C screening and treatment for people with lived experience of homelessness: A mixed-methods systematic review

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Abstract

Background: People experiencing homelessness have an increased risk of hepatitis C virus (HCV) infection, with rates higher than the general population. However, their access to HCV diagnosis is limited and treatment uptake is low.

Objectives: To identify and describe the barriers and facilitators for HCV screening and treatment for adults with lived experience of homelessness in highly developed countries.

Methods: Bibliographic databases (Embase, MEDLINE, CINAHL and SocINDEX) and grey literature (Google, EThOS, the Health Foundation, Social Care Online, the World Health Organisation, Shelter, Crisis and Pathway) were searched. Two reviewers independently screened and appraised all studies. The Critical Appraisal Skills Programme tool and the Joanna Briggs Institute checklist were used. The analysis involved a three-stage process: coding, theme generation and theme mapping under Penchansky and Thomas's modified access model.

Results: Twelve papers/reports were included in the review. Several interacting factors influence access of people with lived experience of homelessness to HCV testing and treatment. Some mirror those identified for the general population. The precarious conditions associated with the lived experience of homelessness along with the rigidity of hospital settings and lack of awareness emerged as dominant barriers. Flexibility, outreach, effective communication, tailoring and integration of

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Funding information

None

services were found to be important facilitators. Evidence from Black, Asian and minority ethnic groups is limited.

Conclusions: People experiencing homelessness face multiple barriers in accessing and completing HCV treatment, relating to both their lived experience and characteristics of health systems. Although some barriers are readily amenable to change, others are more difficult to modify. The facilitators identified could inform future targeted measures to improve HCV diagnosis and treatment for people experiencing homelessness. Research is warranted into successful models to promote screening, diagnosis and treatment.

Patient or Public Contribution: Our team includes a peer advocate, a hepatology nurse and a community volunteer, all with significant experience in promoting and engaging in HCV care and outreach for people experiencing homelessness. They contributed to the protocol, interpretation and reporting of the review findings.

KEYWORDS

adult, delivery of health care, hepatitis C, homeless persons, humans

1 | INTRODUCTION

Hepatitis C virus (HCV) is a blood-borne virus that can cause liver disease.¹ Intravenous drug use is the main mode of transmission.² In 2015, it was estimated that 71 million people worldwide had a chronic HCV infection.³ This is associated with a significant risk of developing liver cirrhosis and cancer.⁴ People with a history of homelessness in high-income countries experience severe inequities across a number of health conditions, including HCV.⁵ This is due to various interacting socioeconomic factors that shape conditions of daily life, many being beyond an individual's control.^{6,7}

Intravenous drug use is highly prevalent among the homeless community, increasing their risk of infection with blood-borne viruses.⁸⁻¹⁰ Although the overlap between the number of people experiencing homelessness and those using drugs is difficult to estimate, the UK and international literature indicate that it is significant.¹¹ A systematic review and meta-analysis conducted in 2012, found that the prevalence of HCV in homeless populations ranged from 3.9% to 36.2%.¹² A more recent review in the United States showed similarly wide-ranging figures from 9.8% to 52.5%.¹³ In homeless shelters in London, 13% of those who agreed to be screened ($N = 491$) had past or current HCV infection.¹⁴ The highest risk of HCV was identified in individuals reporting injecting drug use. However, even those without injecting drug history had higher levels of HCV than the general population (3% vs. 0.4%).¹⁴

A new class of drugs to treat HCV: direct-acting antivirals (DAAs) are now available. They require a shorter treatment time, with better success rates and fewer adverse effects than interferon. However, access to HCV diagnosis and treatment among the homeless community remains low. In the study of Aldridge and colleagues,¹⁴ participants diagnosed with current HCV, showed poor engagement

with health services, with over half of those referred to specialist services either not attending appointments or being lost in follow-up. This concurs with other studies showing suboptimal uptake of HCV treatment among people experiencing homelessness.^{15,16} Some factors influencing HCV testing, management and uptake of care have been identified at the societal level (e.g., social stigma against people experiencing homelessness).^{17,18} Others have been identified at levels of the system (e.g., logistics in booking appointments, workforce constraints at homeless shelters). Individual factors (e.g., precarious living conditions, competing priorities, limited knowledge and misconceptions regarding HCV) are also evident.^{17,18}

Equity of access is a central objective of many healthcare systems.¹⁹ Access has been conceptualized in various ways, demonstrating its complexity.²⁰ Most commonly, it is described as the interaction of factors that impact entry to or utilization of a health system. Some authors interpret access as the population's ability to seek and secure care, while others put more emphasis on the characteristics of the health system that influence utilization of services.²⁰ Some conceptualize access as the 'fit' between the patients' needs and the characteristics of health systems,²¹ a notion whose complexity highlights the importance of analysing access from a multidimensional perspective.

Despite the high prevalence of HCV among people experiencing homelessness, a significant number remain undiagnosed and hence untreated, with reasons for the low engagement and uptake of HCV care being unclear.²² Previous systematic reviews have focused either on people who inject drugs or those leaving prison.^{23,24} A better understanding of the factors influencing HCV screening, and treatment uptake and adherence among the wider at-risk population of people experiencing homelessness, is crucial to guide the development of effective programmes tailored to their complex health needs.¹⁷ Universal access to affordable diagnostics and treatment is

also important in achieving the WHO's 2030 target for elimination of HCV and reducing health inequities.²⁵

Therefore, this systematic review aimed to answer the question:

What are the barriers and facilitators for HCV screening and treatment for adults with lived experience of homelessness in highly developed countries?

2 | METHODS

2.1 | Protocol and registration

The review protocol was registered a priori with PROSPERO (registration number: CRD42020221767). The conduct and reporting of the review was guided by ENTREQ²⁶ and PRISMA guidelines.²⁷

2.2 | Eligibility criteria

Eligibility criteria were used at both title/abstract and full-text levels as described in Table 1. There were no date or language restrictions.

2.3 | Information sources

The literature searches were designed and undertaken by an information specialist (L. Burns) on 3 December 2020 (from the inception of the respective database to December 2020). The databases searched were Embase, MEDLINE, CINAHL and SocINDEX. Grey literature was searched using Google, EThOS, the Health Foundation, Social Care Online, the World Health Organisation,

Shelter, Crisis and Pathway. Citation searching of included studies and relevant systematic reviews was also conducted.

2.4 | Search

The search used both index and title abstract terms for the concepts of homelessness and HCV. Full details of the search strategies used in all databases are provided in Supporting Information File 1.

2.5 | Study selection and data collection process

Search results were collected and deduplicated in EndNote and then uploaded onto Rayyan for screening.²⁹ Screening on title/abstract and full text, was conducted by two independent reviewers (M. P. and N. C.). Any disagreements were resolved through discussion, consulting a third reviewer (J. S.) if there were no consensus. Data from studies that were included in the review were extracted using a pilot-tested form. Information extracted included author, year, setting, type of homelessness, sampling, data collection method(s), participant characteristics, barriers and facilitators.

2.6 | Critical appraisal

The studies were critically appraised independently (M. P. and N. C.) using the Critical Appraisal Assessing Skills Programme tool for qualitative studies and randomized controlled trials (RCTs)³⁰ and the Joanna Briggs Institute checklist for cross-sectional studies.³¹ Agreements were reached through discussion and consultation with a

TABLE 1 Eligibility criteria

Population/participants	Inclusion: Adults aged 18 years with current or previous experience of homelessness, and/or staff, volunteers and healthcare professionals working with homeless populations. Exclusion: Nonadult populations (<18 years). The European Typology of Homelessness was used, which includes the following living situations: <ul style="list-style-type: none"> • rooflessness (without a shelter of any kind, sleeping rough) • houselessness (with a place to sleep but temporary in institutions or shelters) • living in insecure housing (threatened with severe exclusion due to insecure tenancies, eviction, domestic violence) • living in inadequate housing (in caravans on illegal campsites, in unfit housing, in extreme overcrowding).²⁸
Phenomenon of interest	Access (to a service, provider or an institution) and utilization (realized access) of HCV screening and treatment among people with lived experience of homelessness.
Outcomes	Perceived barriers and facilitators to HCV screening and treatment for people with lived experience of homelessness from their perspective, and/or that of support workers and volunteers, and healthcare providers.
Type of study	Inclusion: Empirical studies using qualitative, quantitative and mixed methods. Exclusion: Reviews, letters, commentaries and editorials, conference abstracts.
Location of study	Inclusion: Countries of very high Human Development Index (HDI) to improve transferability of findings to advanced healthcare systems and services. Exclusion: Countries of high, medium or low HDI. HDI Table 1: Human Development Index and its components. Available at http://hdr.undp.org/en/composite/HDI

Abbreviation: HCV, hepatitis C virus.

third reviewer (J. S.) when required. No studies were excluded through the critical appraisal.

2.7 | Synthesis of findings

Included full-text qualitative articles were uploaded onto NVivo 12 software (QSR International Pty Ltd, 2020). The analysis involved a three-stage process: coding, theme generation and theme mapping.

2.7.1 | Coding

Firstly, participant quotations and authors' interpretations were inductively coded line-by-line by two independent reviewers (M. P. and N. C.)³² using semantic analysis.³³ Descriptive coding labels were used to enable both the codes and future themes to be freely formed, rather than influenced by an a priori deductive framework developed by the authors. This aligned with our research aims to appropriately utilize and build upon existing knowledge published in this field, by synthesizing existing findings.

2.7.2 | Theme development

In the second stage of analysis, reviewers drew upon an adjusted approach to thematic synthesis³² to facilitate identification of patterns within a data set³⁴ and enable researchers to stay close to the findings of primary studies, transparently linking them to conclusions made.³²

Initially, M. P. and N. C. independently reviewed whether inductive codes could be grouped under the headings 'barriers' and 'facilitators', addressing the key research question of the study. They independently examined the similarities and differences between the codes grouped under these two headings to build descriptive themes, which captured patterns of findings across the studies.

The reviewers then discussed their decisions on grouping the codes and emergent themes, initially comparing their themes and addressing variances by adjusting/adding/merging their combined themes to reach a consensus on each. They subsequently reviewed and agreed whether each theme should be classified as a barrier or facilitator. Through these independent and joint processes, the reviewers kept the research question and aim of the study in mind. This approach to synthesizing the findings enabled this study's findings to move beyond the content of the original studies,³² providing analytic (latent)³³ insights.

Quantitative results were inputted in an Excel file independently by M. P. and N. C., following consensus meetings to ensure consistency. These were codified (i.e., data transformation) and grouped, based on whether they were relatable to the qualitative 'synthesised' themes. The findings for each theme were then examined to establish whether they reinforced or challenged the findings each theme presented. Thus, the review used an integrated design whereby both

quantitative and qualitative data were assimilated into a single synthesis^{35,36} in which they could be "able to confirm, extend, or refute each other".³⁵

2.7.3 | Theme mapping

Following the completion of the inductive process, it became apparent that the emergent themes were relatable to Penchansky and Thomas's modified access model, which interprets access as the degree of 'fit' between the patient and the service.^{21,37} To explore the extent of the fit between this study's 'synthesised themes' (which were not changed to fit the model), they were mapped to each dimension included within the 'modified access' model: (1) awareness, effective communication with relevant users, including consideration of context and health literacy; (2) acceptability, the attitude of the patient towards the care provider and service characteristics and the attitude of the provider towards patients' personal characteristics; (3) accommodation (how well the service is organized to access patients and how well patients are able to use the services); (4) affordability, direct and indirect costs for the patients; (5) accessibility, the proximity to the patient and (6) availability, sufficient supply of services required to meet patient needs.^{21,37,38} Although independent, these dimensions are interrelated and each is important to assess the achievement of access.³⁷ The model's core principle is to optimize access by accounting for these dimensions.³⁷ Therefore, it was deemed useful to undertake the mapping and organize the findings through this established model to draw attention to issues relating to the model that had not been addressed in the existing literature and/or service provision, and identify measures that could improve access to HCV care among people experiencing homelessness. The wider team was invited to review the findings and contribute to their interpretation; results were adjusted accordingly.

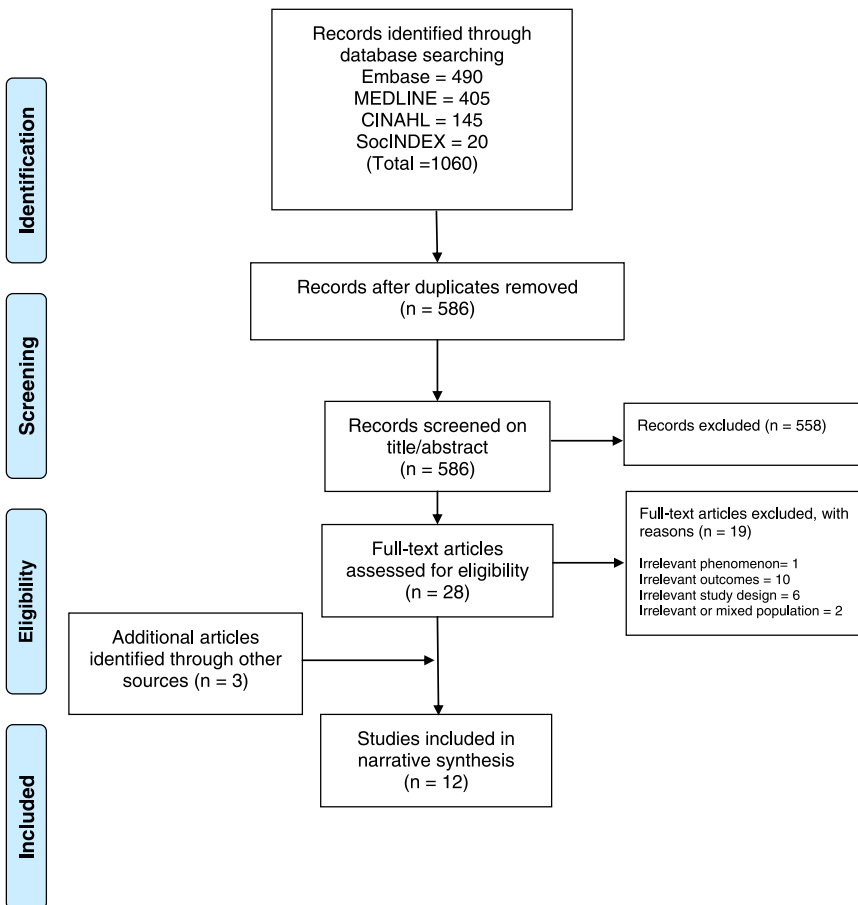
3 | RESULTS

The search results at each stage are shown in the PRISMA figure below (Figure 1).

Initially, 1060 papers were identified. Following deduplication, 586 papers were screened on title and abstract. Screening on full-text was conducted on 28 papers, of which 9 were included in the review, plus 3 identified through searching grey literature, giving a total of 12.

The studies used qualitative ($N = 9$) or quantitative ($N = 3$) methods; one of the latter was an RCT. The studies took place in the United States ($N = 6$), the United Kingdom ($N = 5$) and Ireland ($N = 1$) and in various settings/contexts including: clinics within a programme of healthcare for people experiencing homelessness (a freestanding outpatient clinic, a medical respite facility, a clinic located in a day shelter and a clinic within an emergency shelter) ($N = 1$); homeless shelters ($N = 3$); research cohorts ($N = 4$); outreach hepatitis C testing and intervention (for those in temporary accommodation) ($N = 1$);

FIGURE 1 PRISMA flow chart



outreach services for drug use and homelessness offering point of care HCV, hepatitis B virus and HIV testing ($N = 1$); an outreach HCV treatment clinic established within a primary care facility ($N = 1$); a community-based partnership offering HCV treatment and support to people who inject drugs in a drug and alcohol support programme plus a community-based HCV outreach service ($N = 1$). Studies commonly adopted purposive sampling. In the majority, the target population was living in unstable housing. In most studies ($N = 9$), participants included those with experience of homelessness and ranged in age from 26 to 65+ years. In one study, one of the participants was in the age category of 16–25 years. Two of the studies focused on people who inject drugs, the majority of whom were experiencing or had experienced homelessness. Five studies focused on or included healthcare providers, support staff (including peer supporters) or both. The others ($N = 7$) focused exclusively on people who have experienced homelessness. In total, 986 people with experience of homelessness and 104 staff members participated in the studies. No study appeared to have included people sleeping rough. However, the participants' detailed living situation was not always reported. In eight out of the nine studies that included people with experience of homelessness and from which data could be extrapolated, the majority of participants were males (for the other one, there was an equal representation of males and females). Out of eight studies that provided data on ethnic background, the participants were predominantly White/Caucasian in five, predominantly of Black

or racial/ethnic minority background in two, and in the remaining one, the distribution was almost equal. Participant and study characteristics are detailed in Supporting Information File 2.

The findings from the critical appraisal were mixed (Supporting Information File 3), with quantitative studies (except the RCT) commonly scoring lower on their quality. In qualitative studies, the relationship between the participants and researchers was commonly not reported. Insufficient reporting rendered the quality assessment of two out of the three grey literature reports difficult. All studies contributed to the review's findings; however, those of lower quality provided less data.

Table 2 illustrates the subthemes identified under each dimension of Pechansky and Thomas' modified model. Illustrative quotes for each domain are included in Supporting Information File 4.

3.1 | Awareness (communication and information)

3.1.1 | Barriers

Limited knowledge and/or misconceptions regarding HCV can make people experiencing homelessness reluctant to get tested. This may relate to knowledge on modes of transmission, testing, diagnosis and availability and advances in treatment.^{17,18,39} Limited advocacy for services by shelter staff, who themselves reported their own low

TABLE 2 Subthemes identified from data analysis

Dimension	Subthemes
Awareness	
Barriers	Limited knowledge regarding HCV and associated care among people experiencing homelessness and among support staff Misconceptions Negative stories about experiences of interferon treatment Limited advocacy for HCV services by shelter staff Fear of receiving positive results
Facilitators	Raising awareness among people experiencing homelessness and among shelter staff about HCV, treatment, etc. Improving awareness about addiction issues among service providers Outreach activities
Acceptability	
Barriers	Mistrust of healthcare providers and government institutions Perceived stigma and discrimination Fear of side effects of treatment Strict eligibility criteria
Facilitators	Effective communication and relationships with staff Patient centred services Nourishing relationships with partners and families Prompts by providers Integrating rapid HCV testing in the intake process of shelter settings Transitioning into a healthier life
Accommodation	
Barriers	Lived experience of homelessness and associated morbidities Unstable housing Incarceration Illegal residency status Limited language skills Inflexibility with the appointment system and timings Lack of appropriate infrastructure to treat HCV and workforce constraints at the shelter level Shelter policies and rules, e.g., around drug use
Facilitators	Providers' organizational leadership and culture Multiagency partnership building Information sharing Peer support Ensuring privacy Reminders Establishing clear communication channels
Affordability	
Barriers	Perceived cost of treatment High out of pocket expenses Lack of insurance coverage Strict insurance requirements
Facilitators	Improving awareness of welfare programmes and resources

TABLE 2 (Continued)

Dimension	Subthemes
	Providing support with accommodation or transport Financial incentives
Accessibility	
Barriers	Distant location of clinic or hospital Lack of transport
Facilitators	Adaptable model of delivery Continuity of care Proximity of clinics Integration of services at one location
Availability	
Barriers	Intermittent attendance Long time between diagnosis and treatment Long time to wait on the day
Facilitators	Short waiting times Flexibility and adaptability

Abbreviation: HCV, hepatitis C virus.

HCV treatment knowledge, may be a barrier to testing and treatment.¹⁷

Negative stories about past experiences of interferon treatment (i.e., long duration; adverse effects), can affect the current uptake of screening, testing and treatment.¹⁷ People experiencing homelessness reported that fear of a positive diagnosis and the consequences of being infected demotivated some people from getting tested, while others did not feel the need to get tested due to low perceived risk.¹⁸

3.1.2 | Facilitators

Homeless shelter users reported that education is crucial in motivating people to get tested and treated for HCV.¹⁸ Preventing transmission to others, along with awareness of the adverse effects of untreated HCV can significantly motivate people to be tested and treated to prevent their own disease from progressing.¹⁸ Raising awareness that HCV is curable has been recommended.^{17,18} Increasing awareness and understanding among patients, providers and key stakeholders of the benefits of treatment with DAA agents, including duration of treatment and less challenging side effects, is important.^{17,18} HCV outreach educational programmes in settings frequented by people experiencing homelessness⁴⁸ can give the opportunity to spend time talking to people and dispelling misinformation about HCV as well as addressing stigma.³⁹

The importance has been highlighted of nurses who are delivering HCV treatment also having knowledge of addiction issues, and for key workers to have a basic understanding of treatment.⁴⁰ Providing education for shelter staff can increase their self efficacy to support their clients' awareness and treatment needs.¹⁷ Providing

CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests.

ETHICS STATEMENT

Ethical and patient consent statements are not applicable for this article.

AUTHOR CONTRIBUTIONS

Martha Paisi made substantial contributions to study conception and design, and acquisition, analysis and interpretation of data; drafted the manuscript and revised it critically for important intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Neeltje Crombag made substantial contributions to study conception and design, and acquisition, analysis and interpretation of data; revised the manuscript critically for important intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Lorna Burns made substantial contributions to study conception and design, and acquisition of data; revised the manuscript critically for important intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Annick Bogaerts made substantial contributions to study conception and design; revised the manuscript critically for important intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Lyndsey Withers made substantial contributions to study conception and design, and interpretation of data; revised the manuscript critically for important intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Laura Bates made substantial contributions to study conception and design, and interpretation of data; revised the manuscript critically for important intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Daniel Crowley made substantial contributions to study conception and design, and interpretation of data; critically revised the manuscript critically for important intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Robert Witton made substantial contributions to study conception and design; revised the manuscript critically for important

intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Jill Shawe made substantial contributions to study conception and design, and analysis and interpretation of data; revised the manuscript critically for important intellectual content; gave final approval of the version to be published; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

DATA AVAILABILITY STATEMENT

All data generated or analysed during this study are included in this published article [and its supplementary information files].

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: Paisi M, Crombag N, Burns L, et al. Barriers and facilitators to hepatitis C screening and treatment for people with lived experience of homelessness: A mixed-methods systematic review. *Health Expect*. 2021;1-13. doi:10.1111/hex.13400