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BMJ Open Transformation of identity in substance use as a pathway to recovery and the potential of treatment for hepatitis C: a systematic review protocol

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ABSTRACT

Introduction Hepatitis C virus (HCV) is a strongly stigmatised disease as it is framed within the context of injecting substance use. HCV provides the identity of ‘dirty’ or ‘junky’, with perceptions by others being beyond the control of the individual. People who experience problematic substance use are often viewed as being outside acceptable social behaviours, thus viewed as having tainted identities or second-class citizens. It is suggested that to recover from substance use, people should move towards social networks where substance use is not the norm and there is greater recovery support. The social identity model of recovery advocates that the mechanism to do this is by developing a new identity. It is unclear what catalysts provide this change in identity. This systematic review aims to describe actions, interventions and treatments that provide the opportunity for new identities and considers evidence that supports the hypothesis that curing HCV with direct acting antivirals may provide this opportunity.

Methods and analysis Methods are informed by the Preferred Reporting Items for Systematic reviews and Meta-Analysis statement. Seven electronic peer-reviewed and four grey literature sources were identified and preliminary searches have been conducted. The inclusion and exclusion criteria are broad to capture activities that result in a change in identity, recovery from substance use, quality of life, life satisfaction or the opportunity for the individual to reclaim their place in society (citizenship). Qualitative and quantitative literature are eligible. Papers will be assessed against standardised criteria and checked independently and in duplicate. A narrative synthesis of the findings will be reported, structured around intervention type, population context and outcomes.

Ethics and dissemination This systematic review will be based on studies that have already been conducted and therefore no ethical approvals are required. The resulting findings will be submitted to an international peer-reviewed journal and disseminated at relevant research conferences.

PROSPERO registration number CRD42020209447.

INTRODUCTION

Problematic substance use has wide and far reaching health and social consequences for individuals and communities.^{1 2} Injecting

Strengths and limitations of this study

- To our knowledge it is the first systematic review on this topic.
- The study design includes a large grey literature search component to minimise publication bias and independent double-screening and coding to minimise selection bias and data errors.
- The study is restricted to English language evidence and has a Western-culture bias (although the latter is by design) which may limit application of findings.
- There is potential bias in the review design because of the research team’s prior knowledge of hepatitis C virus treatment, recovery from substance use and citizenship literature which may have influenced the research questions.

drug use is strongly stigmatised within society; those who participate are regarded as acting outside of acceptable social norms and as a result are often viewed as having tainted identities and as second-class citizens.³

Health risks inherent with injecting drug use mean that people with a current or past history are the key risk group for hepatitis C virus (HCV) infection.⁴ As HCV is framed within this context, it is often perceived to be a shameful and stigmatising disease providing an identity of ‘junkie’, ‘dirty’, with perception by others being beyond the control of the individual.^{3 5–9}

The introduction of direct acting antiviral (DAA) drugs to treat HCV transformed care, providing highly effective (~96% cure rate), simple and quick treatment regimes with few side effects. This is a vast improvement from care experienced in the interferon-era where treatment was arduous with only moderate cure rates.^{10–14} The paradigm shift to DAAs were heralded as a technology of hope, providing the stimulus to realise the WHO’s target of eliminating HCV as a public health concern by 2030 through increased treatment

uptake and reaching the most marginalised.^{5 10 11 15–17} However, while DAA treatment may be less onerous, significant barriers, such as stigma and competing priorities remain and further action is required to reach the key risk group to address the low number of people engaging with HCV testing and treatment.^{18–21}

People who inject drugs are suggested to be looking for a cure beyond HCV as a reason to engage with treatment; the opportunity for an untainted identity, recovery from substance use and social redemption.²² Understanding and communicating how DAAs may provide these wider non-clinical benefits may present compelling evidence for this group to engage with treatment.

Identity transformation is a key component of recovery from substance use.^{23–28} Social identity provides a sense of who you are based on the group(s) of people with whom one associates with, which in turn shapes ones behaviours and influences health and well-being.^{26 29 30} Social identity may provide support and positive influences on health behaviours, however, it may also influence negative lifestyle choices and create a barrier to recovery.^{24 31} The concept of a Social Identity Model of Recovery proposes that recovery from substance use relies on an intertwined shift in self-identity and social identity. The change in self-identity of the individual towards a ‘recovery’ identity shapes their social network to one where the use of drugs is not the social norm.^{23 27 32} This social network, away from substance use re-enforces the ‘recovery’ self-identity and also provides a recovery enabling environment, a key factor recognised in building recovery capital.

Recovery capital is a theoretical construct that describes the social, cultural, physical and human capital that can be brought to bear on the initiation and maintenance of recovery from dependent substance use.³³ Recovery from substance use is defined as a process that encompasses other markers of progress towards overall health such as emotional well-being, and building and maintaining relationships. An integral part of recovery is reintegration into the community³⁴; not just physical citizenship but also being part of society; being a citizen in everyday life.³⁵

The catalyst that provides the change in self-identity that may propel an individual down a recovery pathway to reclaim their place in society remains unclear. The purpose of this review is to provide information about the types of interventions, treatments or actions that provide the opportunity for a change in identity and support a recovery journey. The review will also specifically consider if treatment for HCV with DAAs provides this catalyst. Developing this knowledge may provide compelling evidence to engage in testing and treatment at an individual and society level. The review may also identify new avenues for research for the delivery of the WHO targets for HCV elimination

Objectives

To our knowledge, no systematic reviews with a similar aim have been conducted previously. Guided by the research objectives numbered below, this systematic review aims: To

Table 1 PI(E)COC

Population	People in recovery from dependent substance use; illicit use and prescription medicine misuse, including alcohol and excluding tobacco.
Intervention/Exposure	Any action, treatment or intervention for substance use or related health issue.
Comparator	Any or none.
Outcomes	The opportunity for a change in identity and support for a recovery journey.
Context	From the UK and countries culturally similar to the UK (USA, Canada, Australia, New Zealand, Western Europe).

review the existing literature on recovery from substance use and provide a comprehensive overview on the role a change in identity has in propelling an individual down a recovery pathway. To provide a commentary on the types of actions that may cause a change in identity and consider if treatment with DAAs for HCV provides this opportunity.

1. Determine interventions, treatments or actions related to substance use that result in a change in identity.
2. Describe the impact a change in identity has on a recovery journey, quality of life, life satisfaction and citizenship.
3. Consider evidence for change of identity as a result of treatment for HCV with DAAs.

METHODS AND ANALYSIS

The systematic review will include studies that meet the eligibility criteria and the objectives set in PI(E)COC (table 1) which outlines the criteria for the population, the intervention/exposures under review, comparator, outcomes of interest and context/setting of the study.

Eligibility criteria

The search will be conducted in the relevant databases and grey literature sources outlined in this protocol. The inclusion and exclusion criteria are broad to capture activities that result in a change in identity, recovery from substance use, quality of life or life satisfaction or the opportunity for the individual to reclaim their place in society (citizenship). Quantitative and qualitative studies will be included in this review.

Population

The population of interest are people with a reported current or past history of dependent substance use, defined by diagnosis or behavioural indicators, such as injecting drug use. Substance use may include illicit use or prescribed medication misuse (where use is for a purpose other than that prescribed and in a manner that has a negative impact on health and/or functioning)

and dependent and harmful alcohol use. Tobacco use is excluded as it is outside the scope of this systematic review.

Interventions and exposures

Any action, treatment or intervention for substance use or related health issue, for example, HCV, HIV, hepatitis B, bacterial infection, chronic pain and mental health problems will be included in this review. Health issues wider than HCV, but related to substance use have been included in this review as they are often intertwined and there may be transferable learning. Interventions, treatment or actions delivered via a community programme, citizenship programme, rehabilitation or treatment programme will be included in the systematic review. Community programmes and citizenship programmes are defined as structured programmes that enhance community and social opportunities for people who use drugs who experience social exclusion as a result of stigmatisation and marginalisation. Any treatment or intervention identified that does not report on recovery or a change in social or self-identity will be excluded. Papers without sufficient data to determine the inter-relatedness of the intervention, action or treatment and a change in identity or the connection between identity and recovery will also be excluded.

Comparator

Studies with no comparator or control are included in this systematic review as the purpose of the review is to identify treatments or interventions that result in the outcomes previously outlined. The purpose of the study is not to compare treatments or interventions.

Outcome

The studies must report outcomes of a recovery journey from substance use and a change in identity. Recovery can mean different things to different people. Recovery may be measured using quantitative or qualitative tools, described by participants or as a secondary measure. Recovery journeys may include, but are not restricted to, abstinence, reduced frequency of drug use, social functioning, employment status, community activity, citizenship (reclaiming place in society) and changes in self-identity towards a recovery identity, social identity change through a shift in social networks towards groups that provide support for recovery, recovery capital, self-concept, quality of life and well-being. Studies that are related to recovery from substance use where there is no measure of a change in identity, change in quality of life, life satisfaction or citizenship (reclaiming place in society or undertaking activities thought of as normal expected activities of citizenship) are excluded.

Context

Primary qualitative and quantitative studies will be included which are published in the English Language since the year 1991, since this is the year that interferon became commercially available to treat HCV. The data must relate to people reporting a history of dependent

substance use and be from countries culturally similar to the UK (USA, Canada, Australia, New Zealand and Western Europe) to allow appropriate comparisons to be made.

Patient and public involvement

Patients and public were not directly involved in the design of this study. As this is a protocol for a systematic review and no participant recruitment will take place.

Information sources and search strategy

The following electronic databases will be systematically searched using a mix of free text terms and indexed terms: MEDLINE, EMBASE, PsycINFO, ProQuest Public Health, ProQuest Sociological Abstracts, CINAHL and Web of Science (core collection from 2010 to 2020). The search strategy for the electronic databases is informed by the PI(E)COC components described above. It combines free text and database-specific index terms related to the Population (eg, terms for substance users/use, addiction and history of addiction); terms related to the Intervention or Exposure (eg, terms for intervention, treatment, therapy, rehabilitation, abstinence and recovery); and terms related to Outcomes (eg, terms for identity, citizenship, social norms, reinvent, stigma and social group). The strategy is limited to results published in 1991 to date, since this was the year that interferon was commercially available to treat HCV and limited to English language papers only. A grey literature search of conference material from the International Network on Hepatitis in Substance Users, Society for the Study of Addictions annual symposium, Lisbon Addictions conference and Improving Outcomes in the Treatment of Opioid Dependency conference from the year 2010 (where available online) will also be conducted to identify further studies and mitigate potential bias to the review from locating studies from peer-reviewed journals only. If additional studies are identified from the conference materials and full papers are not available, authors will be contacted for draft papers. Conference abstracts will be included if full or draft papers are not available. A copy of the search strategy is included in online supplemental appendix 1.

DATA

Data selection and coding

The results from the systematic search will be combined using EndNote (Clarivate) V.X9 and duplicate results removed. The remaining results will be evaluated by two authors (AR and SRD) who will perform an inclusion/exclusion criteria-based screening of the titles and abstracts. A minimum of 15% of preliminary screened articles will be screened together to ensure consistency in screening methodology and both authors will independently screen all results. EndNote V.X9 will be used to manage the screening process. Once the initial screening step is complete all full texts of the remaining results will be independently screened by two authors (AR and SRD).

In cases of disagreements at each step, a third author (JFD) will be consulted to assist in reaching a decision.

A Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) flow diagram will be included in the systematic review to describe the selection process. After the initial screening process the exclusion reason for full article screening will be recorded and reported using the PI(E)COC criteria set out in this protocol. If a result is excluded due to a number of criteria the reason for exclusion will follow the PI(E)COC order. For example, a result excluded due to participants and context will be recorded as exclusion due to participants.

Data extraction

Data will be extracted from the relevant studies. To allow for a narrative synthesis of qualitative and quantitative results, the discussion section of studies reporting quantitative results will be used for thematic data extraction. Key characteristics of study design, participant characteristics, results (including themes and quotes), context and author interpretations will be extracted into a spreadsheet and coded in NVivo (QSR international) V.12 independently and in duplicate by two authors (AR and SRD). Studies will be coded into pre-existing concepts, with new concepts were created when required. Any disagreements will be discussed by the two authors and if a decision cannot be reached, a third author (JFD) will be consulted.

Risk of bias (quality) assessment

The relevance of included selected studies will be assessed in duplicate by two authors (AR and SRD) using the study inclusion criteria (above), and the rigour and validity of included studies will be evaluated using the relevant Critical Appraisal Skills Programme (CASP) checklist for the study design.³⁶ The CASP checklists will be used to systematically appraise the methodological quality of the studies. If a study methodology is considered to be inappropriate to address the aims of the research, it will be discussed by both authors (AR and SRD) to determine if it should be included in the review. In cases of disagreements, a third author (JFD) will be consulted to assist in reaching a decision.

Synthesis and analysis

The selected studies will be subject to thematic synthesis based on written information by the authors and data (eg, quotes/transcripts) documented. All studies selected for review will have the full texts read by both authors to identify and gain consensus of themes. Themes will be identified through an inductive approach through discussion between authors, Where there are disagreements, they will be discussed between both authors (AR and SRD) with a third author (JFD) consulted as arbitrator when required

If necessary data are available, studies will be grouped according to participant characteristics (such as gender, employment, education). As this is a qualitative synthesis, it is not possible to specify groups in advance. A narrative

synthesis of the findings will be reported, structured around intervention type, population context, and outcomes.

This protocol adheres to the PRISMA-P 17 item checklist^{37 38} to ensure that the resulting systematic review is robust and transparent and any changes to the protocol will be reported and explained. A copy of this checklist is included in online supplemental appendix 1. The resulting systematic review will be checked against the PRISMA statement prior to submission for publication.³⁹

Potential implications

This systematic review may provide information about the types of treatment or interventions that provide the catalyst for a change in identity which may propel an individual with (problematic/dependent) substance use down a recovery pathway. This review may provide evidence to suggest that treatment and cure of HCV using DAAs may provide the type of catalyst required to initiate this change, therefore may provide additional reason to engage with DAA treatments at an individual and societal level. Additionally, this systematic review may identify new avenues for further research.

ETHICS AND DISSEMINATION

This systematic review will be based on studies that have already been conducted and therefore no ethical approvals are required. This systematic review has been registered on PROSPERO and the resulting paper will be submitted to a peer-reviewed international journal. The resulting findings will also be disseminated at relevant research conferences. Any amendments to the protocol will be registered on PROSPERO.

Review status

At the time of submission, the systematic search has been completed and duplicate search results have been removed. The screening process of titles and abstracts has started and the planned review is expected to be complete by October 2021 with report submission in December 2021.

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Contributors SRD wrote the protocol for the systematic review, performed the preliminary searches, will conduct data extraction, quality assessment and thematic analysis and will draft the systematic review paper. AR contributed to the design of the systematic review and will conduct data extraction, independent quality assessment and independent thematic analysis. JFD made substantial contributions to the design of the systematic review and, if required, will assist SRD and AR to resolve any discrepancies regarding study inclusion, data extraction and quality assessment. All authors contributed to revisions to the protocol manuscript and will contribute to the systematic review manuscript.

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Patient consent for publication Not applicable.

Ethics approval This study does not involve human participants.

Provenance and peer review Not commissioned; externally peer reviewed.

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SUPPLEMENTARY MATERIAL

Appendix 1

Search Strategy

MEDLINE

Search: Topic 1 terms (all OR'd) AND Topic 2 terms (all OR'd) AND Topic 3 terms (all OR'd)

PI(E)COC

Topic 1: Population – substance users (terms below), substances, addiction terms, history, career,

"Substance-Related Disorders" OR "Drug Abuse" OR "Drug Addiction" OR "Drug Dependence" OR "Drug Habituation" OR "Drug Use Disorders" OR "Organic mental disorders, substance-induced" OR "Prescription Drug Abuse" OR "Substance Abuse" OR "Substance Addiction" OR "Substance Dependence" OR "Substance Use Disorders" OR "Substance Misuse" OR "Substance Use" OR "Substance career" OR "Substance history"

Topic 2: Intervention – intervention, treatment, therapy, rehabilitation, abstinence, recovery,

"Intervention" OR "Treatment" OR "Therapy" OR "Rehabilitation" OR "Abstinence" OR "Recovery" OR "Medication Assisted Treatment of Opioid" OR "Opiate Medication-Assisted Treatment" OR "Opiate Replacement Therapy" OR "Opiate Substitution Treatment" OR "Opioid Medication Assisted Treatment" OR "Opioid Replacement Therapy" OR "Opioid Substitution Therapy" OR "Opioid Substitution Treatment"

Topic 3: Outcomes – recovery, recovery capital, quality of life, wellbeing, stigma

"Recovery" OR "Recovery Capital" OR "Quality of Life" OR "Life Quality" OR "Health-Related Quality of Life" OR "Wellbeing" OR "Capability Approach" OR "stigma" OR

"Citizenship" OR "Citizen" OR "Active citizen" OR "Participating Citizen" OR "Identification, social" OR "Group Identification" OR "Social Identity" OR "Social Network" OR "Self-concept" OR "Self-identity" OR "Identity" OR "social group" OR "social norms" OR "reinvent" OR "identity"

Appendix 2

PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol*

Section and topic	Item No	Page Number	Checklist item
ADMINISTRATIVE INFORMATION			
Title:			
Identification	1a	1	Identify the report as a protocol of a systematic review
Update	1b	N/A	If the protocol is for an update of a previous systematic review, identify as such
Registration	2	2	If registered, provide the name of the registry (such as PROSPERO) and registration number
Authors:			
Contact	3a	1	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author
Contributions	3b	13	Describe contributions of protocol authors and identify the guarantor of the review
Amendments	4	11	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments
Support:			
Sources	5a	13	Indicate sources of financial or other support for the review
Sponsor	5b	13	Provide name for the review funder and/or sponsor
Role of sponsor or funder	5c	13	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol
INTRODUCTION			
Rationale	6	3-5	Describe the rationale for the review in the context of what is already known
Objectives	7	5-6	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)
METHODS			
Eligibility criteria	8	6	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review
Information sources	9	8-9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage

Search strategy	10	8-9	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
Study records:			
Data management	11a	9-10	Describe the mechanism(s) that will be used to manage records and data throughout the review
Selection process	11b	9	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)
Data collection process	11c	10	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators
Data items	12	7-8	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications
Outcomes and prioritization	13	8	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale
Risk of bias in individual studies	14	10-11	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis
Data synthesis	15a	10	Describe criteria under which study data will be quantitatively synthesised
	15b	10-11	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2 , Kendall's τ)
	15c	n/a	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)
	15d	10	If quantitative synthesis is not appropriate, describe the type of summary planned
Meta-bias(es)	16	N/A	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)
Confidence in cumulative evidence	17	10-11	Describe how the strength of the body of evidence will be assessed (such as GRADE)