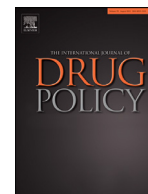




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## Review

## Conceptualising hepatitis C stigma: A thematic synthesis of qualitative research

Magdalena Harris<sup>a,1</sup>, Danielle Guy<sup>b,1</sup>, Camila A Picchio<sup>b</sup>, Trenton M White<sup>b</sup>, Tim Rhodes<sup>a</sup>, Jeffrey V Lazarus<sup>b,c,\*</sup><sup>a</sup> Department of Public Health, Environments and Society, London School of Hygiene & Tropical Medicine, 15-17 Tavistock Place, London WC1H 9SH<sup>b</sup> Barcelona Institute for Global Health (ISGlobal), Hospital Clínic, University of Barcelona, Calle del Rossellón 132, ES-08036 Barcelona, Spain<sup>c</sup> Faculty of Medicine, University of Barcelona, Barcelona, Spain

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## ABSTRACT

**Background:** Stigma is an important element in the experience of living with chronic viral hepatitis B (HBV) and C (HCV), impacting healthcare access and uptake as well as health outcomes. Conceptualisations of stigma in research are, however, often assumed and implicit. This study aimed to synthesise and critically engage with the qualitative literature to provide an overarching conceptualisation of stigma as it pertains to viral hepatitis.

**Methods:** We critically reviewed qualitative literature that mobilised concepts or theories of stigma in relation to viral hepatitis. We searched seven electronic databases for peer-reviewed literature from 2000 to 2019. Given a dearth of conceptual literature on HBV stigma, we conducted a thematic analysis of concepts deployed to theorise stigma in relation to HCV.

**Results:** We found 13 studies that conceptualised stigma in relation to HCV, yet none for HBV. We synthesise the analytical findings of these studies and explore how HCV is theorised in relation to four themes: 'identity', 'embodiment', 'institutionalisation', and 'structuration'. Taken together, these themes illustrate the way in which HCV stigma manifests as the confluence of normative assumptions of socially unacceptable practices relating to HCV, such as injecting drug use and sexual behaviours; attitudes towards socially excluded populations; and fears of contracting a contagious and chronic illness. As such, operating within political, social, and economic systems, HCV stigma can act to silence the needs of those with HCV through misrecognising the multifaceted identities of individuals with HCV and structural determinants of health. Stigma, which is built and perpetuated by institutional arrangements, as well as in social processes and policies, shapes deservedness to, as well as engagements with, health and social care.

**Conclusion:** While commonly employed as a framing concept, much research lacks explicit theoretical or critical engagement on how stigma is conceptualised. There is a tendency for qualitative, empirical research to focus on risk factors shaping individual behaviour change, rather than on risk contexts and socio-structural change. Approaches to address stigma in relation to HCV must consider how stigma operates throughout social processes and is embedded in systems of power and normalised in institutional operating systems.

## Introduction

Chronic viral hepatitis B (HBV) and hepatitis C (HCV) infection is a major public health threat and affects an estimated 325 million people globally. If left untreated, viral hepatitis can lead to hepatocellular carcinoma and cirrhosis, and contributes to some 1.4 million deaths an-

nually (World Health Organization, 2016). However, the vast majority (290 million) of people with viral hepatitis are unaware of their status and are therefore not engaged with the formal healthcare system for viral hepatitis care and treatment. The World Hepatitis Alliance has emphasised social stigma as a critically important factor shaping access to viral hepatitis testing, diagnosis, and care (World Hepatitis Alliance, 2018). Addressing stigma is a key step towards reaching national and global targets to eliminate viral hepatitis as a major public health threat (A National Strategy for the Elimination of Hepatitis B & C, 2017; Commonwealth of Australia, 2018; World Health Organization, 2016). A well-established body of literature traces stigma

\* Corresponding author.

E-mail address: [Jeffrey.Lazarus@isglobal.org](mailto:Jeffrey.Lazarus@isglobal.org) (J.V. Lazarus).<sup>1</sup> Contributed equally.<https://doi.org/10.1016/j.drugpo.2021.103320>

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and its adverse effects as a common feature of the lived experience of viral hepatitis, primarily arising from misconceptions of infection and transmission (Dowsett, Coward, Lorenzetti, Mackean, & Clement, 2017; Lee, Fawcett, Kim, & Yang, 2016; Liu, 2016; Mokaya et al., 2018; Paterson, Backmund, Hirsch, & Yim, 2007; Treloar, Rance, & Backmund, 2013). Additionally, many individuals with viral hepatitis belong to marginalised populations, such as people who are experiencing homelessness or who use drugs, or engage in practices which are subject to various forms of stigma, such as injecting drugs (World Health Organization, 2017). Stigma is also reproduced in healthcare practices and settings (Mokaya et al., 2018; Paterson et al., 2007), resulting in fragile trust in experts and services (Treloar, Rance, & Backmund, 2013), especially amongst those most vulnerable with least access to care (Harris, Ward, & Gore, 2016; Rhodes, Harris, & Martin, 2013). Consequently, experiences of stigma can preclude access to care and deter help-seeking, even in the face of need (Lee et al., 2016; Liu, 2016; Rhodes et al., 2013). As such, understanding how stigma entangles with viral hepatitis, and how such stigma affects health-seeking behaviours, access to care, and the care received, is fundamental to addressing viral hepatitis (World Health Organization, 2017).

A paradigm shift in HCV treatment (Cooke et al., 2019), accompanied by a global commitment to eliminate viral hepatitis as a major public health threat by 2030 (World Health Organization, 2016), requires reconsideration of stigma as a mobilising concept that informs healthcare and other interventions. A growing body of literature measures stigma in relation to viral hepatitis using quantitative indicators, metrics, or scales, based on recalled and reported lived experiences (Cotler et al., 2012; Drazic & Caltabiano, 2013; Paterson et al., 2007; Saine et al., 2020; Soltan, Salama, & Aboelmagd, 2018). The translation of stigma into indicators enables mapping and monitoring in relation to the frequency, intensity, and location of stigma occurrences, which can then be linked to analyses of risk or health outcomes (Butt, Paterson, & McGuinness, 2008). Much of this work, however, does not explicitly define or unpack what is meant by ‘stigma’ per se, but assumes a shared understanding. Qualitative studies provide valuable insight into the ways in which stigma is experienced and how these impact health outcomes and decision-making processes (Butt et al., 2008). However, even within qualitative research, conceptualisations of stigma tend to be assumed and implicit rather than carefully delineated and critically reflected upon. In this review, we synthesise concepts generated from a smaller body of qualitative research in which there is an explicit theorisation or critical engagement with stigma as it pertains to viral hepatitis.

At the time of writing, there has been no targeted synthesis of the conceptual literature on viral hepatitis-related stigma. An early review (Paterson et al., 2007) sought to critically examine published research representations of HCV stigmatisation, with a focus on how these understandings have informed healthcare interventions. Similar to other research (Van Boekel, Brouwers, Van Weeghel, & Garretsen, 2013), the thematic presentation of findings of Paterson et al. (2007) are orientated towards elucidating the determinants of HCV stigma in healthcare settings, rather than to conceptual development or critique. Likewise, Treloar, Rance, & Backmund (2013) in a later review maps HCV stigma in relation to healthcare uptake and access, highlighting the modifying role of trust in facilitating relationships of care, but stops short of critically reflecting upon how the social construct of stigma itself is to be operationalised or theorised going forwards. More recent reviews act to map determinants of stigma (Saine et al., 2020) or synthesise literature on living with HCV with attention to the pervasive and detrimental impact of stigma on people’s lives (Dowsett et al., 2017).

A lack of critical attention to the concept of stigma itself is due in part to the influence of Goffman’s definition of stigma as an “attribute which is deeply discrediting”, whereby those who are stigmatised become “reduced in our minds from a whole and usual person to a tainted, discounted one” (1963, p. 3). Notwithstanding this seminal contribution of stigma as a social construct, an implicit or uncritical application of Goffman’s conceptualisation risks focusing on stigma as an “individual

**Table 1**  
Inclusion and exclusion criteria.

| Inclusion   | Exclusion   |
|---|---|
| Original academic research  | Editorials, commentaries, reports, or reviews   |
| Use of qualitative methodology such as focus groups, interviews, and observations (can be part of a larger mixed-methods study) | No use of qualitative methodology (e.g., surveys and questionnaires)  |
| Published from 2000 to 2019   | Published before 2000   |
| Explicit engagement, analysis, or theorisation of stigma associated with viral hepatitis  | Description of stigma associated with viral hepatitis without further engagement, analysis, or theorisation |
| Published, peer-reviewed research   | Research not yet published or peer-reviewed   |
| Reported in English or Spanish  | Reported in any language other than English or Spanish  |

tragedy”, best ameliorated through individualised coping methods and interpersonal level interventions (Link & Phelan, 2001; Parker & Aggleton, 2003). In making this critique, Link and Phelan (2001) alert to the role of power and structural inequity in the manifestation of stigma, through processes such as labelling, stereotyping, and discrimination (Link & Phelan, 2001). Recent contributions to the field, and specifically in relation to drug use and viral hepatitis, highlight stigma and its effects variably, for instance, as a matter of socio-political relations (Fraser et al., 2017; Seear, 2020; Tyler & Slater, 2018), or discursive practices (Toyoki & Brown, 2014). As such, ‘stigma’ is not a singular or stable category, but rather it is open to theorisation and deployment in research in variable ways; as further illustrated in this review.

### Methodology

In this review, we map the ways in which stigma, as it pertains to viral hepatitis, has been variously conceptualised in a select body of qualitative literature. Through thematic analysis and synthesis of the concepts deployed, we aim to advance theory building with a practical remit of informing future stigma reduction interventions for people living with viral hepatitis.

### Eligibility criteria

Included studies were original, peer-reviewed, qualitative research, including ethnographies or case studies, that include perspectives of people living with viral hepatitis or their care providers (see Table 1). We included studies published from 2000 to reflect advances in stigma theorisation over the past two decades and to coincide with the launch of the Millennium Development Goals, reflecting a renewed global focus on infectious diseases. Studies must have generated analyses in relation to viral hepatitis stigma and also to have provided an explicit conceptualisation of stigma in this context.

As the aim of this paper was to synthesise conceptualisations of stigma related to viral hepatitis within the qualitative evidence base, we excluded studies that reference stigma as a taken-for-granted concept without providing any definitional work around the term. While we recognise that qualitative studies may produce empirical descriptions which can then be theorised, we only included studies that provided an explicit theorisation of stigma related to viral hepatitis. We also excluded editorials, commentaries, and reviews. The reference lists of reviews were, however, searched to find additional studies and frame the synthesis rather than to be incorporated as material for the main analysis.

**Table 2**

Search strategy example.

|                |    |   |
|----------------|----|---|
| Web of Science | #1 | 'viral hepatitis' OR 'Hepatitis C' OR 'Hepatitis B' OR 'HCV' OR 'hep c' OR 'hepatitis c' OR 'hepatitis c virus' OR 'hep c virus' OR 'HBV' OR 'hep b' OR 'hepatitis b' OR 'hepatitis b virus' OR 'hep b virus' |
|                | #2 | 'social stigma' OR 'social discrimination' OR stigma' OR prejudice OR attitude OR marginalization OR shame  |
|                | #3 | 'qualitative research' OR qualitative OR interview OR 'focus group' OR experience OR perception OR ethnography OR perspective   |
|                | #4 | #1 AND #2 AND #3  |

### Information sources

In December 2019, we searched the following electronic databases: PubMed, Medline, CINAHL, Anthropology Plus, SocIndex, PsycINFO, and Web of Science from 2000 to 2019. Search terms included terms related to viral hepatitis, stigma, and qualitative research, and MeSH were used where applicable (see Table 2). We also conducted forward citation searching of relevant articles using tools in PubMed and Google Scholar.

### Study selection

After running the initial search, articles were imported into Mendeley Desktop version 1.19.4. After removing duplicates, articles were broadly screened from search output on the basis of titles and abstracts by DG. DG conducted forward searching and hand-searched the references of these eligible articles for those not indexed in the selected databases. These articles were then screened on the basis of titles and abstracts by MH and TR, disagreements were resolved with DG and JVL. After screening based on titles and abstract, articles were screened on the basis of full-text for inclusion by DG, CAP, TMW, and MH. Disagreements were resolved with JVL.

### Data collection process and data items

Two independent reviewers (DG and CAP) extracted data into a pre-specified data extraction template. Information included authors, title, study aims, design, setting, population, stated theoretical or analytical framework, methods of data generation and analysis, and a brief summary of how stigma was conceptualised by the authors. Data were extracted by one reviewer (DG) and validated by another (CAP). Differences were reconciled amongst three reviewers (DG, CAP, TMW).

**Table 3**

Analytical codes.

|     |   |
|-----|---|
| 1.  | Stigma is conceptualised as intrinsic (self-stigma and felt stigma)                               |
| 2.  | Stigma is conceptualised as extrinsic (enacted stigma)  |
| 3.  | Stigma is organised hierarchically in relation to HIV   |
| 4.  | Stigma is organised hierarchically in relation to social status                                   |
| 5.  | Stigma is mediated by social or community identity/ownership                                      |
| 6.  | Stigma is lessened/worsened depending on HCV transmission route                                   |
| 7.  | Stigma arises from conflation of HCV and injecting drug use or people who use drugs               |
| 8.  | Stigma comes from the belief that those with HCV engaged in what is deemed as "risky behaviours"  |
| 9.  | Stigma emerges from fear of contagion of illness  |
| 10. | Stigma is rooted in ignorance, which stems from misconceptions and stereotypes of people with HCV |
| 11. | Stigma stems from societal aversion to chronic illness  |

### Synthesis of results

Given the absence of eligible studies addressing conceptualisations of stigma related to HBV, we focus this analysis on HCV. Since the overarching aim of studies reviewed did not have to relate to advancing stigma theorisation, we did not assess the strengths and limitations of conceptualisations of HCV stigma in this regard. We conducted a thematic synthesis based on principles of grounded analysis and meta-ethnography methods (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). The concept synthesis was grounded in reading of articles reviewed and a two-stage inductive coding process, rather than being determined by a priori topics. Drawing on the framework of Thomas and Harden (2008), three reviewers (DG, CAP, TMW) independently analysed each study, assigning first level codes to describe concepts deployed in relation to HCV stigma. Summaries were made for each text to consolidate and aid thematisation of the key conceptual findings. Following this round, five reviewers (DG, CAP, TMW, JVL, and MH) discussed and worked with first level codes and summaries to consolidate and abstract them into 11 main analytical codes (see Table 3). Summaries were then created for each of these codes, which the five reviewers worked with to consolidate into four conceptual themes relating to identity, embodiment, institutionalisation, and structuration.

Three reviewers (DG, CAP, TMW) were randomly assigned one third of the articles to code the text against each conceptual theme. The coding for each article was then validated by a second reviewer from this same group to ensure consistency. Disagreements were resolved amongst all three reviewers.

### Results

#### Study selection

The initial search yielded 3,085 records. After removing duplicates, 2,998 total articles remained. After screening, 87 articles remained. Following searching and hand-searching the references of the initial articles, 12 additional articles were considered for eligibility. From these articles, 31 were reviewed at the full text level for final inclusion. Eighteen articles were excluded, primarily because they mentioned stigma but did not theorise or conceptualise what was meant by the term, and specifically in relation to HCV (see Fig. 1).

#### Study characteristics

Thirteen studies were included in this review (see Table 4). Studies took place in Argentina ( $n = 1$ ), New Zealand and Australia (1), Australia ( $n = 4$ ), Canada ( $n = 2$ ), the United Kingdom, ( $n = 2$ ) and the United States ( $n = 3$ ). Across all studies, there were 447 participants; sample sizes ranged from 6 to 132. The study participants described in the studies included healthcare workers ( $n = 2$ ), people with chronic HCV ( $n = 10$ ), people living with HIV ( $n = 2$ ), and people with HCV and

**Table 4**

Characteristics of included studies.

| Author (Date)   | Study aims  | Country        | Population and sample size  | Qualitative method   | Theoretical/ analytical framework   | Conceptualisation of HCV-related stigma   |
|-----------------|---|----------------|---|--|---|---|
| Northrop (2017) | To examine the dilemmas and negotiations surrounding disclosure of one's HCV status within the health setting     | Australia      | Individuals aged 33–60 years living with HCV in south-eastern Australia (N = 16)                            | Semi-structured interviews analysed using systematic, multi-layered analysis   | Draws on Goffman's (1963) model of actual and virtual social identity, focusing on stigma as a discrediting attribute, and Douglas (1966) notion of dirt and pollution  | Stigma in terms of HCV is built within the wider social context of the issue. The lack of alternative narratives of those living with HCV conflate HCV and injecting drug use, and the moral assumptions of this conflation create stigma. That is, those who engage in injecting drug use and other 'deviant' behaviours are deemed 'tainted', as Goffman describes, and therefore less human, which enables conscious or unconscious discriminatory practices towards them by health workers in health care settings. Although, the stigma and shame faced by those with HCV make them reluctant to disclose their status and perpetuate the stigma in the healthcare setting.  |
| Owen (2008)     | To describe the emotional experience of HCV stigma in the context of serosorting for HIV-positive sexual partners | United Kingdom | HIV positive gay men aged 32–43 years living in London (N = 6)  | In-depth, unstructured interviews with questions focusing on the emotional impact of stigma. Emergent themes were analysed and compared to existing literature | Focuses on stigma as an emotional experience which influences social interaction and social processes under the framework of Tomkins (1995) demonstrating that emotions amplify the significance of our social interactions | Within sexual practices between men who have sex with men, HCV is more stigmatising than HIV since HCV is not 'owned' by this community. This demonstrates the hierarchical stigmatisation process. In particular, the fear of HCV can be often rooted in fears of obtaining HCV, complicating the existing troubles of managing HIV, sexual rejection due to HCV status, and lifestyle restrictions due to HCV, which causes the infection to be stigmatised within the community. Furthermore, this leads to social rejection when HCV is disclosed, and creates fear and shame, which prevents some men from disclosing their HCV status, thereby risking HCV infection during sexual practice.  |
| Lekas (2011)    | To explore the impact of the layered stigmas of HIV and HCV on the experiences of felt and enacted stigma         | United States  | HIV/HCV co-infected past and former injecting drug users aged 30–69 years living in New York City (N = 132) | In-depth semi-structured interviews focused on the adaptational challenges facing patients coinfected with HIV and HCV and their coping strategies             | Utilises Scambler's (2004) conceptualisation of felt and enacted stigma   | HCV-related stigma is hierarchised in relation to HIV, with HCV being more stigmatising. This stigma layering could mitigate and lessen exposure to stigma. HCV was perceived as a physical illness caused by a biological agent rather than a moral failing (in comparison to HIV), which decreased or eliminated stigma. It was also perceived as being less dangerous amongst many co-infected patients and their social circles, which contributed to lesser stigma in relation to HIV. Although, stigma in relation to HCV was rooted in the fears of contagion as HCV was represented as a highly contagious disease that could be passed through casual contact. Felt stigma in relation to HCV was intensified due to witnessing discrimination after disclosing their HIV status, which caused participants to anticipate stigma in relation to their HCV status. HCV-related stigma also arose through the association of HCV with drug use and contributed to the discrediting nature of someone with HCV. |

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Table 4 (continued)

| Author (Date)      | Study aims   | Country        | Population and sample size   | Qualitative method  | Theoretical/ analytical framework  | Conceptualisation of HCV-related stigma   |
|--------------------|--|----------------|--|---|--|---|
| Krzczkowska (2019) | To explore the impact of diagnosis, culpability, stigmatisation and disclosure experiences on the lives of patients with HCV | United Kingdom | Males living with HCV aged 53 to 68 years ( $N = 7$ ); Participants contracted HCV via contaminated blood transfusions ( $n = 5$ ) and injected drug use ( $n = 2$ ) | Semi-structured interviews analysed using interpretative phenomenological analysis  | Unclear  | Stigma of HCV is rooted within the socio-political context of acquiring infection. Specifically, stigma is influenced by external attribution of blame and responsibility, as well as levels of distress and uncertainty in response to the diagnosis. Stigma here is associated with type of drug use (e.g., injected v. snorted), duration of drug use, and the inability to 'overcome' addiction. When people self-administered drugs, the blame was more internal and less associated with the diagnosis itself. When people obtained HCV medically (e.g., transfusion) they were more likely to externally blame individuals with HCV.   |
| Butt (2008)        | To identify and describe how people lived with HCV and made self-care decisions  | Canada         | Adults (aged 18 or older) with chronic hepatitis C living in British Columbia ( $N = 26$ )   | An interpretive descriptive method exploring experiences of living with HCV using a modified think-aloud technique                        | Considers stigma as a complex social phenomenon involving individual and societal judgements   | This article focuses on how stigma impacts a patient's self-esteem in relation to their HCV status and how the manifestation of stigma occurs in events and activities with family members, friends, co-workers and in health settings. Authors categorise the patient's response to the received stigma as intrinsic and extrinsic, labelling associated emotions to each. Stigma associated with HCV arises from cultural fears of contracting HCV and negative views of people who engage in 'risky behaviours', such as injection drug use, and are members of devalued social groups. Because of this association, society views people with HCV as dangerous and/or irresponsible individuals, blames them for having HCV, and expects them to disregard the safety of others and transmit the virus. HCV-related stigma within the Aboriginal Australian population was compounded by issues of power, status, and capital related to colonial legacies. Stigma is conceptualised as devaluing as a consequence of labelling and stereotyping rooted in their cultural notions of shame. Authors also considered stigma associated with the identity of being an Aboriginal Australian and HCV stigma robbed people in the community of the protective factor of community identity. |
| Treloar (2016)     | To examine the stigma experience of Aboriginal Australians living with HCV   | Australia      | Aboriginal adults (aged 18 years and older) living with HCV ( $N = 39$ )   | Interviews following participants' narratives of HCV care were analysed using thematic analysis and interpretive description              | Focuses on stigma as a part of the social processes of power and control that mark individuals or groups for social exclusion and draws on Link and Phelan's (2001) definition of stigma involving stereotyping, separating, and devaluing | HCV-related stigma within the Aboriginal Australian population was compounded by issues of power, status, and capital related to colonial legacies. Stigma is conceptualised as devaluing as a consequence of labelling and stereotyping rooted in their cultural notions of shame. Authors also considered stigma associated with the identity of being an Aboriginal Australian and HCV stigma robbed people in the community of the protective factor of community identity.   |
| Cama (2015)        | To examine experiences of and responses to stigma and discrimination amongst people with HCV who are involved in advocacy    | Australia      | Speakers participating in an HCV advocacy program aged 35–58 years ( $N = 9$ )   | Semi-structured interviews analysed using an inductive thematic approach guided by research on health-related stigma and its consequences | Applies social identity theory, which posits that if group members perceive the conditions imposed upon them to be illegitimate, they may actively seek to change their situation  | HCV-related stigma arises from misinformation about the illness and a fear of its transmission. This causes discrimination against people with HCV, especially in healthcare settings. The infection was typically associated with injection drug use, which made some healthcare workers blame participants for their illness. Ownership and normalisation of HCV through the advocacy program allowed participants to claim their HCV status and make HCV more visible to providers and therefore less stigmatising.  |

(continued on next page)



Table 4 (continued)

| Author (Date)   | Study aims  | Country                   | Population and sample size   | Qualitative method   | Theoretical/ analytical framework   | Conceptualisation of HCV-related stigma  |
|-----------------|---|---------------------------|--|--|---|--|
| Paterson (2013) | To investigate HCV-related stigma within hospitals  | Canada                    | Adult (aged 18 and older) service providers in hospital EDs or community organisations that served people with HCV in Nova Scotia ( $N = 50$ ) | Interpretive description involving individual and group interviews analysed using a constant comparative analytic approach   | Considers the structural components of hospitals as institutions, as well as particular hospital departments, as impacting the way in which healthcare practitioners within that institution or department respond to and treat people who use illicit drugs and are HCV positive, leading to the perception by this population that the institution or department is stigmatising or non-stigmatising. | Stigma in relation to HCV is environmentally embodied. It is conceptualised as a multi-faceted concept that is fostered and supported by internal and external structures. Communication, institutional, and departmental structures within healthcare systems result in structural stigma of people who use illicit drugs that are HCV positive.  |
| Moore (2008)    | To identify and categorise stigmas associated with HCV  | United States             | Individuals with HCV and part of a liver disease support group aged from 35 to 72 years ( $N = 39$ )   | Analysis of written responses to: Have people ever made you feel uncomfortable or upset because you have hepatitis C? Emergent themes were coded and analysed.                   | Utilises Zickmund's (2003) functional definition of HCV-related stigma as being negatively judged by others as the result of HCV status   | Ignorance of HCV in terms of routes of transmission, standard precautions, workplace policies, and medication side effects allows individuals to enact stigma towards people living with HCV and results in discrimination. Awareness and knowledge play a large role in determining HCV-related stigma. Authors argue that if education of HCV is enhanced and addressed this may significantly mitigate stigma and its related consequences.   |
| Pecheny (2007)  | To understand the daily lives and the ways people living with HIV/AIDS and/ or hepatitis deal with their lives  | Argentina                 | Individuals living with either HIV ( $n = 13$ ), HCV ( $n = 5$ ), or both ( $n = 9$ ) and health professionals ( $n = 20$ )                    | Semi-structured interviews (analysis method unclear)   | Draws on Goffman's (2001) distinctions between discredited and discreditable individuals, particularly focusing on the stigmas that affect people and make them discreditable   | Stigma related to HCV, especially in terms of the health system, was built due to its associations with 'risky' behaviours including injecting drug use, in addition to sexual identity, and lifestyle. In terms of the personal disclosures of patients, there was also a 'stigmatising supposition' of innocent victims and those that deserved HCV depending on the mode of infection. Stigma was hieratically organised in relation to HIV, and HIV was more stigmatising than HCV since people generally were less aware of it. |
| Harris (2009)   | To explore the ways in which participants' discursive, intersubjective and embodied experiences interacted to inform their practices around, and understandings of living with the virus. | Australia and New Zealand | People living with chronic hepatitis C aged 25 to 63 living in Auckland, New Zealand ( $n = 20$ ) and Sydney, Australia ( $n = 20$ )           | Reflections of the author's experience with stigma and HCV as well as interactive, semi-structured interviews analysed with attention to narrative structure and emerging themes | Draws on Crossley's (1994) definition of political phenomenology, which recognises bodies as both agents and targets of power intertwined within social, historical, and political processes  | Stigma related to HCV is rooted in 1) the associations between HCV and injecting drug use, which is more vilified than other forms of drug use since it is seen as a bodily violation; 2) misconceptions of contagion due to a lack of public awareness about HCV and 3) societal views on chronic illness as a devalued bodily state and that HCV doesn't fit into the typical illness trajectory since people with HCV may appear to be well externally but face physical symptoms and stigma that make them unwell internally.    |

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Table 4 (continued)

| Author (Date)    | Study aims   | Country       | Population and sample size   | Qualitative method  | Theoretical/ analytical framework   | Conceptualisation of HCV-related stigma   |
|------------------|--|---------------|--|---|---|---|
| Henderson (2018) | To explore the factors that contribute to the building of social stigma of HCV in rural communities. | United States | Individuals in a rural community aged between 31 and 70 ( $n = 30$ ) | Semi-structured interviews analysed using grounded theory methods, including selective coding | Uses Conrad, Schneider, and Gusfield's (1992) symbolic interactionist approach, suggesting that views of morality are determined by the actors, culture, time, and setting in society | HCV-related stigma is built through the development of the social hierarchy in this rural community, which relates to power, status, and social and economic capital. Perceptions of opinion leaders, who are financially secure and mostly elderly, influence the perceptions about community members and build an informal consensus about HCV. Being in the upper class makes it hard to empathise with people struggling with infection, which contributes to stigma. As such, stigma is related to material and structural disadvantages in society. |
| Fraser (2006)    | To explore the relationship between HCV and stigma   | Australia     | Individuals with current or past HCV infection ( $N = 6$ )           | Semi-structured interviews  | Builds on Goffman's theory of stigma, which authors link to the binary logic common to thinking about the body, health, and identity  | Binary thinking (e.g., good/bad, clean/contaminated, well/sick) in Western culture is integral to stigma categorisations. This creates a clear hierarchy between what is deemed as 'good' and 'bad'. Therefore, the idea of being 'spoiled' by having HCV is constructed in similar terms such as purity/infectious and health/sickness. In contrast, the ideal body must be clean (uninfected), closed (not party to the movement of microbes or other matter) and pure (blameless in terms of infection causation).                                     |

HIV co-infection ( $n = 2$ ). Twelve studies analysed transcribed interview data, and one analysed open-ended responses from a mail-in survey.

#### Unpacking HCV-related stigma

We present and critically engage with analytical findings under four themes: identity, embodiment, institutionalisation, and structuration, that serve as conceptual tools in the theorisation of HCV stigma amongst the reviewed studies. We draw on direct quotes of participants' accounts of HCV stigma throughout studies to highlight these themes.

#### Identity

'I'm a father, I'm not my disease, I'm not my illness' (Cama, Wilson, Mackenzie, & Brenner, 2015, p. 423).

Cama et al. (2015) position stigma as subsuming the complexity of an individual's identity to one specific attribute – in this case the 'disease' of HCV. Similarly, the 12 other studies included in this review incorporated identity-based conceptualisations of HCV stigma, whereby stigma acts in concert with social norms to disrupt a person's sense of self and/or their social identity. Many of these theorisations draw on Goffman's (1963) conception of stigma as arising in interplay with societal labelling of and reactions to specific practices or attributes. While hidden, these 'discreditable' attributes threaten identity and when exposed ('discrediting') they can act to 'spoil' a normative or socially acceptable presentation of self (Goffman, 1963). Here, stigma is capacitated through the disavowal of a complex, multifaceted identity.

We can think with this concept also in terms of Becker's (1963) 'master status', whereby one deviant label becomes the entire identity of the individual. Identity-focused conceptualisations of stigma in the reviewed literature highlight the way in which living with HCV discredits in concert with social norms. For example: practices deemed 'de-

viant' such as injecting drug use (Butt et al., 2008; Cama et al., 2015; Harris, 2009a; Henderson & Kawakami, 2018; Krzeczowska, Flowers, Chouliara, Hayes, & Dickson, 2019; Lekas, Siegel, & Leider, 2011; Northrop, 2017; Paterson, Hirsch, & Andres, 2013; Pecheny, Manzelli, & Jones, 2007), 'promiscuous' sexual relations (Henderson & Kawakami, 2018; Lekas et al., 2011; Northrop, 2017; Owen, 2008; Pecheny et al., 2007) or – simply – being unable to seek and hold employment (Harris, 2009a). Negative stereotypes attached to these practices and attributes are often rooted in societal views of morality or productivity and act to diminish the perceived human status of individuals with HCV.

Identity-based conceptualisations of stigma, therefore, highlight viral hepatitis stigma as a form of 'role engulfment' (Schur, 1971), whereby the person's identity is delimited by associations with specific practices (such as illicit drug use) or conditions (such as viral hepatitis). This can be internalised as shame or fear of encountering discrimination ('felt stigma') or enacted in practice through discriminatory behaviour ('enacted stigma') (Fraser & Treloar, 2006; Scambler, 2004). This conceptual focus narrows attention to the way in which experiences of stigma can impact on individual decision-making, for example in relation to the access and uptake of social and healthcare services. Northrop (2017), for example, highlights how felt and enacted stigma experienced following HCV disclosure in the healthcare setting encouraged some participants to change healthcare providers (and not disclose HCV status to the new provider), while others avoided the healthcare system altogether. The decision not to disclose HCV status to a new healthcare provider is here protective, voiced in these terms:

'I want to be treated like every other person ... and at the moment I don't feel I've been treated the same way' (Northrop, 2017, p. 221).

Northrop explicitly draws on Goffman in her conceptualisation of stigma as it relates to HCV. Her participant's decision not to disclose stigma is a form of identity management – a strategic manipulation of

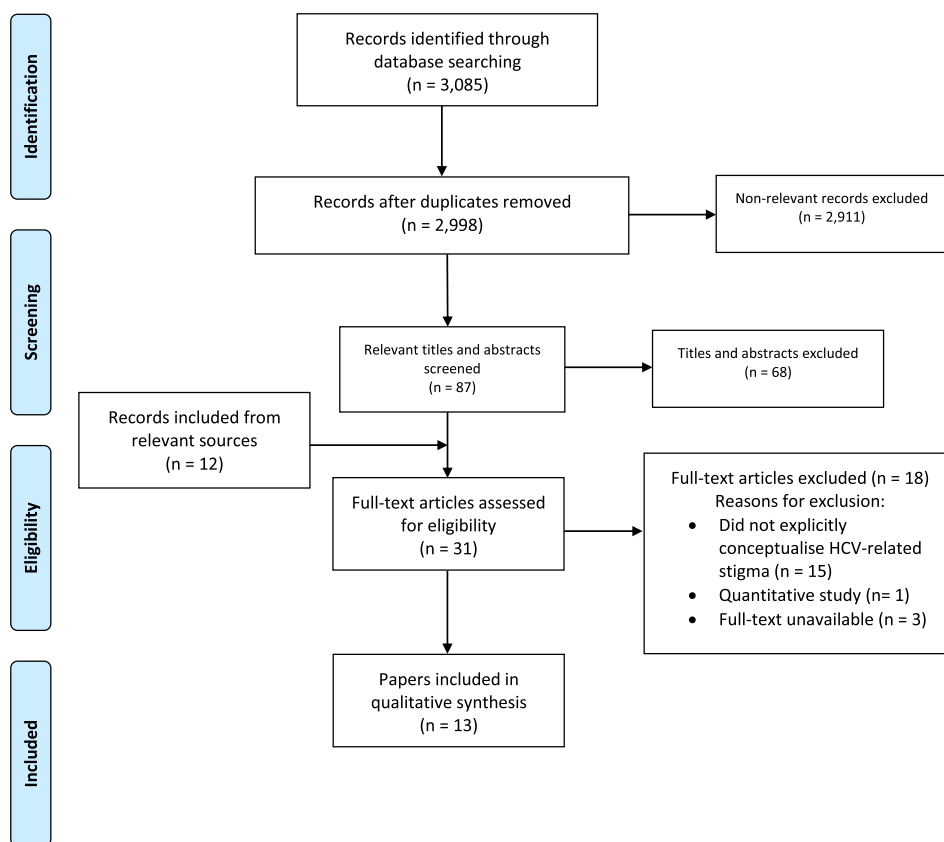


Fig. 1. PRISMA Flow Diagram.

impressions (Goffman, 1959), regulating information to influence the perception of others. Northrop's work is important in illustrating how an individual stigma management focus on regulating interpersonal interactions can have ambivalent effects. In the case above, for example, non-disclosure is deemed necessary to protect the self from judgement and allow some healthcare engagement, but also can be detrimental, precluding care seeking for HCV.

Northrop (2017) also draws on the way in which stigma manifests through the attitudes and actions of healthcare workers as a form of role engulfment. Here, the cognitive processes of healthcare workers are foregrounded in relation to their classification of information and patients according to clinical characteristics as well as medical and social norms. This psychological framing again concentrates attention on stigma as manifest through interpersonal interactions and their effects. Northrop (2017) highlights the way in which conflation of HCV with practices deemed socially unacceptable, such as injecting drug use, can influence (intentionally or not) attitudes towards and treatment of the individual. By subsuming identity to a perceived stereotype or practice, the healthcare worker can cause the patient to feel unsafe or undeserving of care. As demonstrated also by Cama et al., 2015, this limited recognition of full personhood can impair clinical judgement, impact treatment provision and, ultimately, exacerbate health inequalities.

Harris' (2009a) exploration of stigma as experienced by people living with HCV in New Zealand and Australia, also highlights the way in which stigma can manifest through interpersonal interactions as a form of 'role engulfment':

'At the mental health unit [I said] I've got hep C and she [the healthcare worker] said, 'Ah, so you are a junkie.' And I went, 'No, you are judgmental', and then her whole tone changed to, 'So what drugs do you use, how much drugs do you use, do you use heroin?' . . . From the minute I said hep C her whole demeanour changed (Annie, 41)' (Harris, 2009a, p. 38).

As Harris (2009a) elaborates, the positioning of HCV as a 'master status' (Becker, 1963) by the healthcare worker results in Annie leaving the encounter without having her mental health concerns addressed. Not only was Annie's multifaceted identity delimited to the singularity of a presumed 'junkie', but her specific mental health concerns were subsumed to concerns about and causative assumptions pertaining to illicit drug use. Harris explains further that limiting Annie's full personhood can impact not only her sense of self but also her trust in and subsequent future engagement with the medical system.

Studies also demonstrate how normative ascriptions of a 'master status' according to specific practices or lifestyle choices can act to cohere and create a sense of community or solidarity amongst otherwise disparate individuals. In these works, shared ownership of a practice or condition can diminish the weight given to and impact of any associated stigma. This is highlighted in work addressing HIV activism amongst communities of men who have sex with men (MSM) (Owen, 2008) but also can impact how stigma is differentiated in relation to other practices. Three studies, for example, conceptualise stigma as 'hierarchically' enacted in a context of group norms and solidarity (Lekas et al., 2011; Owen, 2008; Pecheny et al., 2007). In one study amongst communities of MSM, HIV was seen as more accepted than HCV, with group ownership of HIV enacting greater protection against broader societal stigma than afforded to HCV (Owen, 2008). Amongst communities of people who inject drugs, this dynamic was framed as operating in the opposite direction (Harris, 2009b). Two studies revealed that in some cases however, lack of awareness about, or ownership of, an associated 'deviant' practice can diminish stigma (Lekas et al., 2011; Pecheny et al., 2007). Lekas et al. (2011) illustrates this in relation to some people living with HIV and HCV, for whom HCV is decoupled from its morally charged route of transmission and seen purely as a physical ailment. Here, 'deviant' practices cannot assume the master status of the individual and felt stigma is diminished (Lekas et al., 2011).



## Embodiment

Ten of the 13 studies conceptualised HCV stigma as also acting on and through processes of embodiment, with particular reference to the way in which HCV contravenes binary norms of bodily containment and 'health' (Butt et al., 2008; Cama et al., 2015; Fraser & Treloar, 2006; Harris, 2009a; Krzeczowska et al., 2019; Lekas et al., 2011; Moore, Hawley, & Bradley, 2008; Northrop, 2017; Paterson et al., 2013; Pecheny et al., 2007). HCV, as a blood-borne virus, is typified by associations with chronicity and contagion. Transmission via blood is a transgression – an effect of boundless embodiment. Lekas et al. (2011) show how this can cascade to threaten all aspects of interaction, as indicated in quote from a 52-year-old Puerto Rican man:

'Well, there I would say that the majority of the people think that the person who has hepatitis C is a danger; that's the first one. If they are aware that you have that kind of illness, what they do is that they exaggerate everything. If you go to eat in someone's home and they know you have that, the first thing is that they separate the plate and separate the spoon, no kisses on the lips, and be very careful, you know' (Lekas et al., 2011, p. 1213).

Here, the body is always manifest, thus it can be difficult for people living with HCV to dissociate from their embodiment as 'an agent of contagion' (Northrop, 2017 p. 219). Fears of embodiment, reactions of sanitary hypervigilance, and/or 'othering' have a long history as elucidated by theorists, such as Mary Douglas (1966), particularly when blood entry or egress is associated with a 'non-normative' bodily opening, such as intravenous injection (Harris, 2009a). As Fraser and Treloar (2006) explain, blood positive with HCV is seen as contaminated or 'dirty' (p. 103), a potentially immutable status, as indicated by 71-year-old Mona:

'I guess you feel like it's kind of dirty... it's never going to come back as clean blood' (Fraser & Treloar, 2006, p. 103).

Similar to Mona, participant accounts across the studies suggest a fine line between 'It's kind of dirty' and 'I'm kind of dirty'. Here, a perceived pollution of the body, or the blood, cascades to the 'polluted or perilous' self (Northrop, 2017, p. 219). Actions to protect the self from these attributions can preclude needed care engagement as highlighted by Northrop (2017):

'One of the reasons why I really just can't face treatment is that I really don't want to deal with the nurse's reactions to me. I don't want to feel like I'm dirty or diseased, or that I've done something bad or wrong to end up there. And I don't want to deal with their reactions to me, not treating me like they should' (Northrop, 2017, p. 221).

These accounts highlight the symbolic meaning and implied morality of cleanliness as a 'virtue', which can serve to regulate social relations through, for example, HCV risk management (Davis & Rhodes, 2004). As explored in five studies, this embodied stigma or perception of pollution can be exacerbated by common misconceptions about HCV and its transmissibility (Butt et al., 2008; Cama et al., 2015; Harris, 2009a; Lekas et al., 2011; Moore et al., 2008) whereby individuals with HCV are perceived as more contagious than they actually are. Lekas et al. describes 'hygienic degradation rituals' (2011; p. 1212) performed as an extreme or hypervigilant measure to avoid HCV transmission, as evident in the cutlery and dish separation described above. Moore et al. (2008) provide an example of how ignorance about HCV can cause people to take extreme precautions in such a manner:

'A co-worker thought I was contagious and used to spray Lysol on me not to get it' (Moore et al., 2008, p. 98).

Lekas et al. (2011) refer to the perception of the body as a 'vector of infection' when acts like these occur. The distress they cause is a product of embodiment stigma.

Two studies elaborate on how, for people living with HCV, the embodied experience of this illness also fails to fit within normative binary boundaries of illness (Harris, 2009a; Henderson & Kawakami, 2018). It is chronic and, until recently, lacked a simple efficacious cure. Symptomology is ill-defined and poorly recognised, thus individuals with the virus may have their health and ability compromised but appear to be well. Harris (2009a) highlights participants reports of debilitating HCV symptoms (chronic fatigue, nausea, cognitive confusion or 'brain fog') and how their unpredictability of duration or intensity can hinder commitment to social or work engagements. Participants who appeared 'well' and/or were reluctant to disclose their HCV recounted distress and frustration at the lack of recognition experienced for their symptomology. Being perceived as 'malingering' amplified felt stigma and guilt when unable to undertake work or social expectations (see also Henderson & Kawakami, 2018). This could result in further disengagement from social relations, impacting on support available and care seeking opportunity (Harris, 2009a). These works are valuable in further unpacking the way in which HCV stigma operates as a social construct and is imbued within the lived and social body, but as with identity-based conceptualisations, they risk individualising stigma understandings and response. Below, we turn to works in which stigma is highlighted as manifest within institutional and structural relations.

## Institutionalisation

Three studies conceptualised HCV-related stigma as embodied in and 'built' through physical or institutional structures, or the lack thereof, and the social processes to which they lend themselves (Henderson & Kawakami, 2018; Moore et al., 2008; Paterson et al., 2013). Specifically, the distinct features of these structures and social processes build and perpetuate HCV-related stigma. For example, Moore et al. (2008) describe that within the healthcare setting, healthcare professionals and the institutional policies governing the rules of healthcare practice (e.g., triage, security, and confidentiality procedures) can interplay to produce and exacerbate HCV stigma. Similarly, Paterson (2013) argues that the confluence of communication, institutional, and departmental structures within healthcare systems generates structural stigma toward people living with HCV, particularly those who use illicit drugs. These studies both described gratuitous 'flagging systems' to make personnel aware of individuals with HCV within the healthcare system.

'What upset me was, I happen to see my 'folder' and taped across it in big black letters on red tape 'Hep C' (Moore et al., 2008, p. 99).

Here, the systems and forms of communication used within healthcare settings facilitate stigmatisation by normalising HCV as a contagion threat and those who carry it as an 'other' to be avoided.

The apparent visibility of these flagging systems, which go beyond necessary infection control procedures and may violate patient privacy (to other patients, visitors, and staff), can be experienced as additionally dehumanising through contravention of confidentiality concerns:

'Two participants [...] stated that there had previously been a flagging system within one hospital on patient charts 'and a sign on the door to warn staff that the patient was HCV positive' (Paterson et al., 2013, p. 474).

Paterson et al. (2013) notes that this may be a way for practitioners to quickly privilege the health of individuals whose illness are perceived as not self-inflicted, meaning that they are regarded as more deserving of care. They also note that the stigmatisation of people with HCV through this process is exacerbated by institutional constraints of health facilities, such as extended waiting times or the absence of dedicated staff (Paterson et al., 2013). This demonstrates how silence can also act to embed stigma in the built environment. The absence of safe or dedicated spaces for HCV testing and treatment informs structural stigma through negating the specific needs of affected populations. Henderson and Kawakami (2018) elucidate how an absence of investment in HCV

prevention, treatment, and care perpetuated 'long held attitudes [about the 'lower class'] including social stigma of HCV' (p. 3086). Similarly, the lack of expertise of general health staff and the absence of specialist staff to address HCV, such as addiction and mental health specialists, can perpetuate stigma through generating unsuitable, and often negative, responses towards people with HCV, especially those who use drugs (Paterson et al., 2013). Within healthcare settings, this is embedded both physically, by the absence of private spaces for people to disclose their HCV status, and systematically, by the absence of referrals to and from community services (Paterson et al., 2013). Policies that preclude or problematise access to preventative healthcare, such as denial of safe injecting equipment in custodial or hospital inpatient settings, also act to silence through negation of needs, usually met in community settings (Treloar et al., 2016). This is also structurally built by wider governmental policies criminalising drug use (International Network of People Who Use Drugs, 2021), which act to socially reinforce stigma against people who use drugs and, in doing so, perpetuate inequity of opportunity and care (Pecheny et al., 2007). Stigma here is structurally enacted both through silencing a population and denying them the opportunity to have their needs met.

Stigma is also structurally enacted through health practitioners' display of hygienic degradation rituals (Lekas et al., 2011), which amplifies the feeling of "otherness" for those with HCV. Studies highlighted healthcare professionals taking unnecessary precautions once participants' HCV status was disclosed. These included putting on double gloves, plastic shields, and closing off rooms when providing care for with people with HCV, none of which are effective or recommended practices for providing treatment (Moore et al., 2008; Northrop, 2017; Paterson et al., 2013). Whether codified as institutional policies in healthcare settings, or the actions of lone practitioners, the power imbalance represented here can thwart action. As highlighted by Moore et al. (2008), the only option for many, as with this participant, is to disengage:

'I had been going to a dentist for a year or so when I found out I had Hep C. The next time I went to see him, I told him of it. The next time I came, he was dressed in head to foot coverup with plastic type shield (like welder's masque) over his face. I was so humiliated that I never went back' (Moore et al., 2008, p. 99).

### Structuration

Power and structure irrevocably interlink in the mobilisation of stigma as highlighted by Henderson and Kawakami (2018). In the context of a small rural community, they foreground the role of the built environment in not only perpetuating stigma through silencing, but in demarcating informal spaces (such as restaurants) in which those with a disposable income can meet, discuss, and define community concerns, build consensus, and consolidate power. Two other studies (Fraser & Treloar, 2006; Treloar et al., 2016) provide an analytic focus on power as it pertains to HCV stigma – following broader recognition of the need to incorporate a thoroughgoing account of power relations in stigma conceptualisation (Link and Phelan's (2001); Parker & Aggleton, 2003). Parker and Aggleton (2003), for example, position HIV stigma as functioning at the 'intersection between culture, power and difference' (2003, p. 17). It involves the categorisation and construction of differences between people, and, through this, their unequal insertion into systems of power. Fundamentally, this serves to position individuals into the hierarchy of deservedness for care and other resources (Paterson et al., 2013).

For Henderson and Kawakami (2018) HCV stigma is 'built' within rural communities from a confluence of entrenched social norms, power hierarchies, and structural inequalities. Rather than HCV or drug use per se, low socio-economic status acts to demarcate a sector of the population as the 'other'. HCV stigma entangles with poverty – both entrenched through silencing mechanisms by those with the power, social status,

and/or financial resources to influence funding decisions. Budget prioritisation is for community 'beautification' rather than alleviating economic hardship and health inequalities. HCV, positioned as a concern of the 'lower class', is negated. It literally 'does not exist':

'One of the waitresses said sarcastically: '[Hep C] doesn't exist [in the eyes of the upper-class people]!' This lack of recognition from the upper 'clique' impacted the amount of help the community provided to issues relating to hepatitis C' (Henderson, 2018, p. 3091).

The authors attribute the continued increase in HCV cases and other infectious diseases in the rural community to this lack of recognition and inaction in providing adequate HCV prevention. Power disparity, arising from social status and income inequality, perpetuates infection due to the lack of action by those with the power to enact structural solutions.

Similar to Henderson et al.'s (2018) mobilisation of class structures and poverty to demarcate HCV stigma, Treloar et al. (2016) draw on cultural attributions of value and worth to unpack the labelling and devaluing of Aboriginal Australians with HCV. Cultural attributions of value and worth are critically important mechanisms through which power is exercised (Bourdieu, 1987). The stigma associated with being Aboriginal in contemporary Australia stems from colonial legacies of cultural appropriation and decimation that have embedded Euro-centric attributions of worth and associated structural inequalities into the fabric of current Australian society. Treloar et al.'s (2016) Aboriginal participants described an 'automatic expectation' that they would be 'Othered' and judged as having stigmatised conditions, like HCV:

'I think I would have to say that the automatic racist attitude that, you know, you'll come up against, you know, like, I expect you to have these things, you are black. Very negative things' (Treloar et al., 2016, p. 24).

Treloar et al. (2016), highlights how the stigma of having HCV intersects with the stigma of being Aboriginal. Here, having HCV is a 'negative thing', affirming an expected designation as 'other' by non-Aboriginal Australians. Culturally ascribed labels and stereotypes manifest power through upholding social hierarchies based on a history of European expansionism and conquest, which are further perpetuated through ongoing practices of colonisation and structural racism. For Aboriginal Australians, as with people who inject drugs and/or who live in poverty, engrained social ascriptions of 'worth' can elicit shame (Treloar et al., 2016). In this way, stigma serves to further exclude these groups from the rest of society. Moreover, this has serious negative consequences in terms of care, treatment, and overall health. A low sense of self-worth may convince some individuals that they are unworthy of healthcare, thus thwarting care seeking impetus and opportunity (Rhodes et al., 2013).

### Discussion

Our findings support a body of work evidencing the deleterious and pervasive impact of HCV stigma on concepts of self, social relations, and access to as well as quality of care, described here as themes of 'identity', 'embodiment', 'institutionalisation', and 'structuration'. Whilst commonly deployed as a framing concept in qualitative studies seeking to unpack the social relations of HCV and related care, stigma is often a concept taken-for-granted, implicitly described, and rarely explicitly deliberated in research. Conscious that the social construct of stigma is open to variation according to how it is deployed in research as well as how it might be theorised in different methods and epistemologies, we synthesised qualitative research deploying ideas of stigma in relation to HCV to reflect on how the concept is used and how we might better delineate stigma concepts in HCV social research moving forward.

Our first observation is a tendency for stigma to be produced and located in relation to individuals, as a matter of how discriminatory

beliefs and attitudes shape social and self-identity. Here, stigma is mobilised in research as an effect or consequence that is felt, made manifest, and observed in individuals. Paterson et al.'s (2007) conclusion from their review, that the majority of studies addressing HCV stigma and discrimination employ individualistic psychological models of stigmatisation, is still prescient. Positioning stigma as arising from, and residing in, individual practices and attitudes, obscures how stigma might be alternatively located and produced in wider social, political, and economic contexts. We note, for example, a recent systematic review of the qualitative literature on living with HCV that includes synthesis of findings related to stigma *causes* and *responses* (Dowsett et al., 2017). Here, the individual and the interpersonal interaction is highlighted as the site of stigma; stigma is *caused* by associations with non-normative risk practices ('deviant identities'), fear and/or misperceptions regarding transmission. Reported responses and actions orientate toward shame, anger, isolation, non-disclosure, and (less commonly) educating others. These findings align with those thematised against 'identity', but neglect consideration of the way in which stigma is operationalised and institutionalised more broadly. As we elaborate below, stigma is felt and located in individual bodies, but this lived experience cannot be separated from social relations; rather it is a recursive effect of these.

HCV stigma is structured and perpetuated by the policies and built environments which support certain social processes, such as criminalisation of drug use and physical arrangements of healthcare institutions. Within this context, societal disavowal and fear of chronic illness in addition to moral assumptions of practices associated with HCV are mobilised to differentiate those with HCV as the 'other'. This 'social triage' (Nguyen, 2010) positions those with HCV in the hierarchy of deservedness for health and social resources and care (Paterson et al., 2013). For example, HCV stigma commonly manifests as the conflation of HCV with certain high-risk and socially demonised practices, such as injection drug use. Given the social perception that health is an individual responsibility rather than a product of wider structural forces (Peterson & Lupton, 1996; Turner, 1984), this presupposes that individuals with HCV are 'less than fully acceptable patient citizen[s]' (Rhodes et al., 2013, p. 1040) and therefore unworthy of high quality care or even any care at all. Fundamentally, this stigmatisation process fails to recognise the various identities, and roots of these identities, of those with HCV, which problematises meeting their health and social needs.

It is important then, to foster conceptualisations of stigma which incorporate the 'social' as elements of what makes up individual-level stigma effects. Embodiment in this interpretation, and as our synthesis of the qualitative literature indicates, refers to the incorporation of the social. The stigmatised human body is not merely symbolic of a social body and of social norms (for instance, through the discrimination of certain bodies from inclusion or representation in public, populations, communities, and services), but material, in the sense that individual bodies become the corporeal hosts of structural harms (for instance, exhibiting unequal ill health, risk, and felt discrimination). Similar to HIV stigma related to drug use, HCV stigma is a social process, linked to and embedded within other forms of marginalisation, which can exacerbate health inequalities and thus access to care (Collins et al., 2016; Parker & Aggleton, 2003). Furthermore, stigma is associated with levels of community awareness and attitudes about people living with HIV, in parallel to what we found about HCV stigma in terms of community support and group solidarity mitigating stigma (Van Nguyen et al., 2017). This highlights the need for thinking of stigma in relation to matters of a social body, rather than simply in relation to individual human bodies, which is also important for practical reasons, as Metz and Hansen (2014) note, in regard to clinical practice:

'If stigmas are not primarily produced in individual encounters but are enacted there due to structural causes, it then follows that clinical training must shift its gaze from an exclusive focus on the individual

encounter to include the organisation of institutions and policies ... if clinicians are to impact stigma related health inequalities' (Metz & Hansen, 2014, p. 128).

This leads us to consider how embodiments of stigma might be theorised as structural concerns.

Here, Metz and Hansen (2014) propose a framework of 'structural competency' for imagining how healthcare can be provided in ways that recognise and address the social basis of ill health, stigma, and other vulnerabilities. Structural competency finds affinity with socioecological models, which emphasise health and illness as effects of structuration and structural vulnerability, meaning that it is shaped by wider environmental, political, cultural, and socio-economic forces (Rhodes et al., 2012). For example, Bagchi (2020) put forth a structurally competent curriculum for primary care providers in the United States to address opioid use disorder, HIV, and HCV, and their associated stigmas. This curriculum provides concrete examples of how structural forces can be rendered visible in the clinical encounter to recognise harms, reduce stigma, and thus provide a people-centred approach to care. Integral to this course is the emphasis on the historical and social factors that have influenced injecting drug use as well as its risks and consequences in the United States, including the role of pharmaceutical companies in opioid medication advertisements, the racial consequences of the 'War on Drugs' and mass incarceration, and the lack of federal funding prioritisation for HIV and HCV treatments. The curriculum also includes tools to assess structural vulnerability and encourages providers to consider structural factors in their explanation of health outcomes (Bagchi, 2020).

Additional examples of structural interventions to enhance HCV treatment access and uptake include the development of 'enabling environments', such as through flexible modifications to appointment systems, treatment locations, and eligibility requirements (Harris, Rhodes & Martin, 2013). Low threshold community-based testing and treatment provision, including through peer-led initiatives (Surey et al., 2019; Wade, Veronese, Hellard, & Doyle, 2016), can mitigate stigma by challenging the 'arrogant authority' (Hansen & Metz, 2019) often entrenched in hospitals and other traditional healthcare settings. As with moves toward 'structural competency', principles of 'cultural safety' also work to develop clinical awareness of political and social dimensions of health outcomes and care, with a focus on recognising and ameliorating interactions, practices, and structural frameworks that cause marginalised populations to feel unsafe and powerless in healthcare environments (Curtis et al., 2019; Gerlach, 2012). Originating from nursing care for indigenous populations, cultural safety training has been successfully adapted to promote care for people who inject drugs in the Canadian context (Pauly, McCall, Browne, Parker, & Mollison, 2015). Authors argue that providers should consider their own place of privilege and power within their relationship with the patient. Providers must also reflect on how this power imbalance may generate a gap in trust, which may be further eroded by the deployment of stereotypes (e.g. of 'addicts') in the health setting by perpetuating blame and assuming individual responsibility for health (Pauly et al., 2015). Associated hospital-based interventions, such as provision of injecting equipment for inpatients, promote not only safe injecting but send a potent symbolic signal of recognition and acceptance – thus enhancing stigma reduction and care equity more broadly.

The examples above are of small structural changes in clinical practice and training that can have far reaching impact. To paraphrase Metz and Hansen (2014) by acting on 'the pathologies of social and institutional systems' we can 'impact the material realities of people's lives' (p. 129). It is crucial therefore, to look beyond explanations and theorisations of stigma as produced and located in relation to individuals, as a matter of how discriminatory beliefs and attitudes shape social and self-identity. This can lead to narrowly focused educational or attitudinal interventions. Such interventions can act in part to ameliorate discriminatory social relations through enhancing awareness, but they



ultimately fail to support sustained change by neglecting to address the broader social structural context in which stigma is supported, perpetuated, and normalised. As noted in this review, stigma is also socially structured through processes of silencing. An absence of safe or dedicated spaces for people who use drugs to receive HCV care, for example, can perpetuate health inequalities through dissuading access. As Henderson and Kawakami (2018) illustrate, the stigma experienced by their participants living with HCV entangles with poverty and together these interplay to enact a population as 'other' and negate their concerns through limited allocation of resources. Stigma here, is not explicit, but enacted as a social process which locates beyond individuals, whilst entangling them, and matters of personal and social identity, inside wider social relations.

Stigma is then a dynamic and complex process (Seear, 2020). It manifests in interactions amongst individuals, practices, and communities-of-practice. Such interactions take place within moral and political economies of social exclusion, which are shaped by cultural distinctions of value and worth (Bourdieu, 1987; Parker & Aggleton, 2003). As such, socially codified binaries – good/bad, healthy/ill, acceptable/unacceptable – are expressed across various power arrangements (from the local to the global) that allow stigma to persist. Thus, stigma interventions must trouble and disrupt binary logics which afford stigma the possibility to work as an act of power in relation to a certain imagined norm or boundary. This highlights the need for stigma interventions to focus on the interactions which produce stigma effects, that it is neither a simple matter of capacitating individuals, nor a simple matter of adapting structures, but rather recognising and addressing how these both interact in a recursive fashion in a particular setting. Therefore, future applications of research on viral hepatitis must move towards clearly mapped conceptualisations of stigma, and conceptualisations of stigma must emphasise its inter-relational and multifaceted characteristics in specific settings. Stigma, then, manifests as both social practice and lived realities, based on its research and other situated implementations (Fraser et al., 2017; Rhodes & Lancaster, 2019).

### Limitations

Our review is subject to several limitations. First, the review may have been impacted by publication bias as we only included peer-reviewed studies. Although, given the topic of this study, grey literature will most likely not make up a substantial portion of the knowledge base. Second, we only aimed to include papers published in English and Spanish, which may have influenced the geographical distribution of papers. The studies we included primarily came from high-income countries, and HCV stigma may manifest differently in this context compared to the low- and middle-income countries (Nguyen et al., 2019). Third, the review may be subject to selection bias due to the necessary interpretive work required to delimit empirical qualitative research that also incorporated explicit conceptualisation or theorisation of stigma. Lastly, the review methodology may have affected the search results and findings of this study since we excluded papers that may have implicitly rather than ostensibly theorised or conceptualised stigma in relation to HCV. However, the precision and rigid nature of this method allows for a better insight into the knowledge base and can serve as a foundation for future research on this topic.

### Conclusion

Much of the work of hepatitis C and its related stigma fails to explicitly conceptualise or define stigma. A shared understanding is assumed or taken-for-granted, problematising the effective development of interventions to mitigate stigma and enhance access to HCV diagnostics, care, and treatment. Our synthesis of the conceptual literature on HCV stigma provides nuance by moving beyond identity or attribute-based conceptualisations of stigma to unpack how stigma operates as a relational process - constituted in an interplay of social, structural, material,

and embodied relations. As such, interventions to mitigate the impact of stigma must be multifaceted, and attend both to the structural, organisational, policy, and social environments in which stigma is built as well as how it plays out in individual interaction. Future research mobilising stigma as a framing concept must engage more critically with stigma as a multiple and relational category that emerges in specific ways according to its contexts.

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### Declarations of Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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### Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.drugpo.2021.103320.

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