CONCEPTUALISING HEPATITIS C STIGMA: A THEMATIC SYNTHESIS OF QUALITATIVE RESEARCH

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BACKGROUND

WHAT WE KNOW

- Social stigma is a critical component of the lived experience of viral hepatitis, shaping access to viral hepatitis testing, diagnosis, and care.
- Addressing stigma is a key step towards reaching national and global targets to eliminate viral hepatitis as a major public health threat.

WHAT WE DON'T KNOW

- The meaning of stigma as it relates to viral hepatitis

METHODS

- Search in PubMed/Medline, CINAHL, Anthropology Plus, SocIndex, PsycINFO, and Web of Science
- Terms related to viral hepatitis, stigma, and qualitative research

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

METHODS

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

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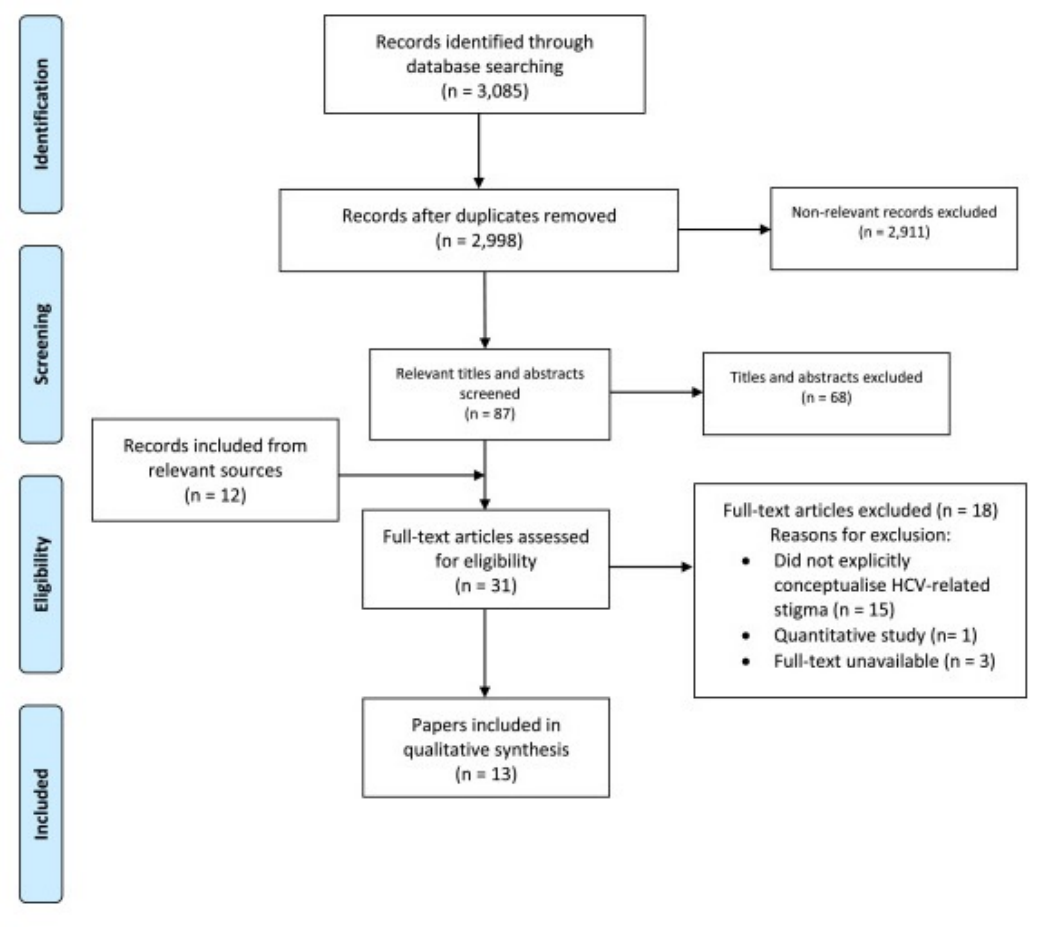
1. Identity
2. Embodiment
3. Institutionalisation
4. Structuration

RESULTS


Identification
Screening
Eligibility
Included
Records identified through database searching (n = 3,085)
Records after duplicates removed (n = 2,998)
Non-relevant records excluded (n = 2,911)
Relevant titles and abstracts screened (n = 87)
Titles and abstracts excluded (n = 68)
Records included from relevant sources (n = 12)
Full-text articles assessed for eligibility (n = 31)
Full-text articles excluded (n = 18)
Reasons for exclusion:
Did not explicitly conceptualise HCV-related stigma (n = 15)
Quantitative study (n= 1)
Full-text unavailable (n = 3)
Papers included in qualitative synthesis (n = 13)

RESULTS: IDENTITY

HCV stigma subsumes the complexity of an individual's identity into one specific attribute, either having HCV or characteristics related to HCV (e.g., injecting drug use).

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 2009)

RESULTS: EMBODIMENT

HCV stigma represents fears of contracting a chronic and contagious illness as people with HCV are viewed as "agents of contagion" (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).

RESULTS: INSTITUTIONALISATION

HCV stigma is embodied in and 'built' through physical or institutional structures, or the lack thereof (e.g., specialist staff, referral to community services), and the social processes to which they lend themselves.

'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).

RESULTS: STRUCTURATION

HCV stigma represents the confluence of social norms, power hierarchies, and structural inequalities, which shapes deservedness and access to care.

'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).

DISCUSSION

- Across the literature, stigma is typically produced and located in relation to individuals, which obscures how stigma might be located and produced in wider social, political, and economic contexts
- 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

RESEARCH INTO PRACTICE: ADDRESSING HCV-RELATED STIGMA

'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' (Metzl & Hansen, 2014, p. 128).

- Structurally competent healthcare education (Bagchi 2020)
- Cultural safety training for practitioners
- "Enabling environments" (Harris, Rhodes, and Martin)
  - Low-threshold, community based services

CONCLUSION

- Research lacks explicit theoretical or critical engagement on how stigma is conceptualised
- Research focuses on risk factors shaping individual behaviour change, rather than on risk contexts and socio-structural change
- Addressing HCV-related stigma must consider how stigma operates throughout social processes and is embedded in systems of power and normalised in institutional operating systems

DISCLOSURE OF INTEREST STATEMENT

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