Reviewer’s report

Title: Living with hepatitis C infection: a systematic review of the literature

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Reviewer: Magdalena Harris

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Living with hepatitis C infection: A systematic review of the literature

This is a well written article and a review of this type is a valued contribution to the literature. The manuscript as it stands, however, requires substantial revision. Specific comments follow:

Major Compulsory Revisions

1. Clarity regarding conceptual framework and objectives

There appears to be a mismatch between the stated objectives and the areas of focus in the manuscript. For example, in the results section of the abstract you open with information on transmission and disease progression risk, which to my reading does not appear to be related to your primary objectives of exploring the social and personal health impacts of living with HCV. So – again, when there are large sections of the manuscript addressing transmission and clinical aetiology/ disease progression – this feels incongruent. For example, in the ‘temporal experience of HCV’ section I am unclear how the quant data regarding transmission incidence and prevalence among cohorts of PWID relate to the temporal experience of HCV, or to the social and personal impacts of diagnosis or to the title of the study ‘living with HCV infection’.

This mismatch could be rectified by clarifying your objectives and conceptual framework. For example – the objectives section of the abstract reads ‘ongoing personal health and social impacts of diagnoses with HCV’. This is somewhat confusing – are you focusing here on the impacts of diagnosis – which implies a certain aspect of living with HCV and a certain point in time, or on experiences of living with HCV more broadly (implied by your title and the ‘ongoing’)? Even if both – the implication is that the area of focus is on the personal impact of living with HCV (social and physical) or more specifically (on reading the background section) the lived experience of HCV over time from diagnosis, a rich and interesting area of focus. In order to do this subject justice in a review of this type, I would recommend seriously considering the need for sections on transmission of HCV and the natural history of HCV – especially as both draw on clinical/quant data that does not appear to speak to your objectives.

It is important you define also what you mean by ‘social’ and ‘personal health’. I would expect ‘social’ to include issues such as impact of HCV on intimate and wider relationships, employment opportunities/experiences, benefit access,
stigma and discrimination, disclosure, social supports, medical encounters, housing access, criminalisation (for PWID – ie impact of incarceration, treatment access in prison etc), gender issues etc and ‘personal health’ to include areas such as illness management, treatment decision making, treatment access and experiences, symptom experiences etc. While some of these areas are mentioned they appear to be rather cursory – and many are not. Obviously, not all of these issues are adequately covered in the literature – but this could be a point of departure for research recommendations. If these issues are not the focus of your review, then that is completely fine – just clarity around the objectives is needed.

2. Clarity regarding chosen search strategy, how it relates to objectives and chosen areas of focus.

The methods section is comprehensive, however I was concerned that your search criteria was overly limiting. I imagine that many studies – especially qualitative - that explore/address experiences of living with HCV, may not come up under the terms: quality of life OR social impact OR socioeconomic impact OR psychological wellbeing. Were these terms specific database subject categories, or key words? They appear to come from a psychology disciplinary angle and may preclude articles which focus more on the social aspects of living with HCV. I would be interested in the rationale for these choices and not others such as stigma, disclosure, relationships, gender, treatment experiences etc.

I am curious to know what is meant by ‘specific data on HCV outcomes’ and why this was an exclusion criteria. It appears to be a rationale for a review of quantitative literature – however the qualitative literature in this field (which may speak more to your stated objectives) may not include ‘specific data on HCV outcomes’. What exactly is meant by HCV outcomes?

3. Referencing!

It is imperative that for a review all statements should be adequately referenced. I was surprised to find a number of sections including no references at all. For example the Social experience of living with HCV section was substantially under referenced. Every statement, such as: ‘exaggerated fears of transmission ... reduced intimacy in relationships’ needs references. Can you expand on what you mean by ‘over-emphasised transmission risks’ – for example in which context, over-emphasised by whom? References are also required here. Again, references are required for the lifestyle modifications such as reductions in alcohol. It is unclear whether these lifestyle modifications took place or are just recommended – and then what impact did this have on the individual’s wellbeing? Again these statements need to be referenced.

There are no references at all in the paragraph ‘over-emphasised ...was reported’ or that beginning ‘infection with HCV had substantial impacts ...’ – it is important for all these statements to be referenced, and also acknowledgement made of the cases where they do not hold, for example there have been studies that have found that the diagnosis of HCV is part of a biographical flow, and is not
experienced as disruptive. A nuanced reading of the literature is required and statements need to be contextualised. For example – the sentence ‘the psychosocial stress ... marginalisation for PWID’ appears to be a supposition bringing together disparate factors from different studies – however, it is hard to tell as not referenced. What is meant by ‘psychosocial stress’ and what other factors may be involved? For example additional factors may include the testing of HCV and HIV at the same time, the positioning of HCV harm reduction within HIV frameworks etc (see papers by Rhodes et al, Harris 2009 etc)

4. Adequate coverage of the relevant literature and results clarity

It feels as if much of the relevant literature has not been addressed in the latter sections – perhaps due to the somewhat restrictive search criteria and again, an apparent mismatch between the objectives and reported findings is reflected in a somewhat thin coverage of the literature in the ‘the social experience of HCV’ section.

What may have been more helpful/interesting for this section or the second search strategy as a whole would have been a meta-analysis of these studies or even demarcation of sections into the primary themes addressed in the HCV social research literature – for example stigma, disclosure, treatment decisions, gendered experiences of living with HCV etc – as these seem to speak so clearly to your overall objectives. While some of these themes are addressed (nothing on gender??) they feel a little thin (much more could be said re treatment decision making for example – and there are more relevant studies during the search timeframe than 5) and could be given sections in their own right. For example, I am not sure the paragraph on stigma, sits well under that of diagnosis as you are referring to stigma in a wider context. The way that structures are productive of stigma such as outlined by Paterson et al., also need to be acknowledged and some demarcation between stigma (felt/perceived) and discrimination made. ‘The social experience of HCV’ section contains a sub-section with the same title – this is a little confusing. How are they demarcated?

Minor Essential Revisions

2. Background section: Over 170 mill people now chronically infected, the estimate of 160 mill requires updating

3. Background section: The second paragraph feels very vague, with many qualifiers. For example, ‘there may be negative social implications within the context of a community who are largely uneducated about HCV transmission’ – what community are you talking about here? Communities of people who inject drugs? The broader public? In which country? HCV is often stigmatised due to its association with injecting drug use – hence there are also negative social implications from correct knowledge about HCV transmission. This paragraph needs to be more concise, and if foregrounding a review – contextualised – this is what we already know, this what we are aiming to find out etc... references are needed for ‘disclosure ... workplaces’. This phrase in the following sentence
‘diagnosis and management impacts are influenced …’ is confusing – not sure what is meant here.

Discretionary Revisions

1. I am curious why you use the term ‘hepatitis C infection’ in the title and body of the manuscript. Possibly consider just using ‘hepatitis C’. Some people living with the virus and community groups find the term ‘infection’ to be offensive/stigmatising – and it is not really necessary.

2. It is unfortunate that there has been lag of a couple of years between when the review was conducted and submission for publication. There has been much written on the subject since, and while I realise this is time consuming the review would be improved if it was updated to include the latest literature. This could potentially be a major compulsory revision dependent on the journals review policy.

3. Background section: As this is article is aimed at an international journal/audience it is preferable if you open to focus on global figures / impact. If Australia is to be a focus this needs to be stated and justified early on.

4. The discussion is good and helps to clarify the conceptual framework of the study. A suggestion is to bring some of this forward to the introduction/background section – to provide a rationale for the longitudinal searches.

Level of interest: An article whose findings are important to those with closely related research interests

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

'I declare that I have no competing interests'