

# Hepatitis C and Ageing

a community brief

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Jacqui Richmond and Jack Wallace



**Australian Research Centre in Sex, Health & Society (ARCSHS)**

Faculty of Health Sciences

La Trobe University

A body politic and corporate

ABN 64 804 735 113

ARCSHS operates from within the academic environment of La Trobe University.

La Trobe University is a Statutory Body by Act of Parliament.

Level 2

215 Franklin Street

Melbourne 3000

Franklin St Campus

Telephone (+61 3) 9479 8700

Facsimile (+61 3) 9479 8711

Email [arcshs@latrobe.edu.au](mailto:arcshs@latrobe.edu.au)

Online <http://www.latrobe.edu.au/arcshs>

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# Executive summary

An estimated 226,700 people in Australia are living with chronic hepatitis C. While the numbers of people estimated to have been infected with hepatitis C has reduced over the past 15 years, the number of people with hepatitis C-related liver disease is increasing. Growing older and duration of infection are significant determinants in the progression to cirrhosis amongst people with hepatitis C. There is a lack of social research describing the experiences of people with hepatitis C as they grow older.

Australia's population is ageing with an increasing number and proportion of people over 65. Government programmatic responses to the ageing population are of a health promotion approach focussing on maintaining older people's health and independence. Less than five percent of older people in Australia live or will live in aged care facilities with a greater emphasis from government policy on keeping people at home: home based aged care services will have an increasingly important role into the future.

This qualitative, interview-based research conducted with key clinical, community and bureaucratic stakeholders in the Australian hepatitis C sector aimed to identify key issues and challenges relating to ageing and hepatitis C to inform future research directions.

While all participants recognised ageing and hepatitis C as a significant issue for Australia, they acknowledged that there was a lack of specific services (clinical and/or community-based) targeting older people with hepatitis C. The lack of services resulted from the limited contact participants had with older people with hepatitis C, and participants expressed concern of their limited understanding of the needs of older people with hepatitis C.

The lack of services is compounded by the variety of definitions of ageing between the research literature, national policy and stakeholder perspectives. For example, the Australia government considers people over 65 years to be "older", whereas in the context of people with hepatitis C, participants described ageing as older than 55 years. An Australian Injecting & Illicit Drug Users League investigation into ageing in 2010 describes people who inject drugs who are over 40 years as ageing.

During interviews, significant attention was directed towards discussing whether “age” is a proxy for “severity of liver disease” or whether there are specific-age related issues associated with mild liver disease. Participants acknowledged that older people with hepatitis C often experience co-morbidities related to ageing, in addition to extrahepatic manifestations of hepatitis C infection, which often complicate the management and treatment of hepatitis C. While the clinical management of hepatitis C is changing and new treatments promise a shorter treatment course with fewer side effects, several clinicians expressed guilt in advising older people to wait for interferon-free regimes because of concern about pre-existing comorbidities, while being concerned that advising older people to wait for three to five years for the new treatments may be too late.

Older people with hepatitis C are not identified as a priority population nor are their needs discussed in the *National Hepatitis C Strategy 2010-2013*. Therefore, it is not surprising that hepatitis C and ageing are not identified as a priority in either the national or state health agenda of the aged care sector. In order to articulate the impact and issues associated with hepatitis C and ageing, the issue of ageing in Australia needs to be examined broadly and the impact of hepatitis C considered in the current context. Exploring the needs of people with hepatitis C as they age needs to occur as a matter of urgency, as older people with hepatitis C are a hidden population. A comprehensive, strategic approach to hepatitis C and ageing is needed to ensure that the needs of older people with hepatitis C do not continue to go unrecognised.

# Background

## Ageing in Australia

Australia's population is ageing, with 14% of the population aged 65 years or over. The number of people aged over 65 years has increased by 641,000 people or 26% since June 2001,<sup>1</sup> and by 2050 people aged over 65 years will make up almost 23% of the Australian population.<sup>1</sup> The issue of ageing is very topical in the general Australian community because the "baby boomer" generation (people born between 1945 and 1965) are growing older and are highlighting the specific needs, services and infrastructure required to support people as they age.

Given the changing demographics, community and government approaches to ageing are adapting. People are retiring later in life, as evidenced by the increasing number of people still participating in the workforce at the age of 65 years and the federal government agenda to increase the official age of retirement.<sup>2</sup> The focus of state/territory and federal government programmatic responses to ageing is shifting towards health promotion for older people.<sup>3</sup> Increased longevity and a higher proportion of people growing older have reorientated the delivery of services to improving nutrition and increasing older people's physical activity and emotional wellbeing. Obviously these health promotion activities will benefit older people with hepatitis C and aim to maintain their long term health, thereby supporting their independence to live at home for as long as possible.

It is worth noting that less than five percent of older people in Australia live in residential aged care services. Indeed the focus of the federal and state/territory governments is to encourage and support older people to remain in their own homes, cared for by family and/or friends for as long as possible.

## Hepatitis C in Australia

In Australia, an estimated 226,700 people are living with chronic hepatitis C, including 49,500 people with moderate to severe liver disease.<sup>4</sup> Although fewer people are acquiring hepatitis C than fifteen years ago,<sup>5</sup> the number of people with hepatitis C-related liver disease is increasing due to the "ageing cohort" effect related to the higher incidence of injecting drug use-acquired infection in the 1980s and 1990s.<sup>6</sup> In

addition, the national hepatitis C notification data shows that the number of older Australians (aged >50 years) diagnosed with hepatitis C has risen from 13% (2,059) in 2007 to 18% (2,393) of diagnoses in 2011. In total, 11,569 people aged over 50 years have been diagnosed with hepatitis C over the last five years (2007-2011) and it is likely that the increasing trend in older people being diagnosed with hepatitis C reflects an increase in late diagnoses rather than new infections. The burden associated with hepatitis C and ageing will continue to rise into the future, with 25% of all diagnoses (n=14,246) made between 2007 and 2011, occurring in people aged 40-49 years.

The lack of symptoms in the early stages of the disease often results in a significant delay between the initial infection and diagnosis. Chronic infection typically results in a slow progression of liver inflammation and scarring. If left untreated it can progressively lead to mild, moderate, or serious liver disease and in some cases, liver failure and liver cancer. Up to 25% of people with hepatitis C will spontaneously clear the virus. Of the remaining 75% who develop chronic infection, between 10 and 20% will go on to develop cirrhosis, or advanced liver disease, and may require a liver transplant. In 2011, hepatitis C infection was the underlying cause of liver disease in 25% of liver transplants.<sup>4</sup> Age and duration of infection of greater than 20 years have been identified as significant risk factors for the development of advanced fibrosis and cirrhosis.<sup>7</sup>

### **Hepatitis C and ageing**

The majority of the evidence exploring hepatitis C and ageing is focused on the clinical consequences of long-term infection with hepatitis C such as advanced liver disease and liver cancer, and the proposed clinical management strategies, namely antiviral treatment. The management and treatment of hepatitis C is currently undergoing a dramatic change with the introduction of Direct Acting Antivirals (DAAs), which are administered for short durations and include the option of interferon-free regimes and medications with fewer side effects. However, the number of people currently accessing hepatitis C treatment remains low (approximately two percent) in Australia.<sup>8</sup> Meanwhile the burden of advanced liver disease associated with hepatitis C is estimated to double over the next two decades unless hepatitis C treatment uptake is increased.<sup>9</sup>

Older people with hepatitis C often present to clinical services for the first time with the complications of advanced liver disease, mainly cirrhosis, liver failure and/or liver cancer.<sup>10</sup> They also experience higher levels of hepatitis C-related morbidity, in addition to the health complications associated with the ageing population more generally such as diabetes, cancer, hypertension and high cholesterol. The frequent morbidity experienced by older people with hepatitis C, along with the significant personal, social and financial costs associated with the infection means that hepatitis C must be acknowledged as a significant public health issue for the ageing Australian population. However, there is no mention of older people with hepatitis C in the current iteration of the National Hepatitis C Strategy.<sup>11</sup>

While the complex processes associated with ageing and Human Immunodeficiency Virus (HIV) have been acknowledged<sup>12</sup> the same attention needs to be given to understanding what it means to grow older with hepatitis C. North American clinical data suggests that the estimated prevalence of hepatitis C cirrhosis and its complications will continue to increase through the next decade and will mostly affect those older than 60 years of age.<sup>13</sup> Further evidence supports the association between ageing, duration of infection and the risk of developing liver cancer.<sup>14</sup>

### **Hepatitis C and ageing among people who inject drugs**

Infection with hepatitis C can have a number of negative consequences on an individual's life.<sup>11</sup> Apart from the obvious health-related complications, stigma and discrimination, social isolation, economic hardship and psychological distress can affect a person's quality of life at any point during their lifespan. People who inject drugs, the population most affected by hepatitis C in Australia, are often confronted with additional challenges when they grow older with hepatitis C.<sup>15</sup> Qualitative research conducted by Australian Injecting & Illicit Drug Users League, identified that many people who inject drugs did not anticipate or prepare for old age, and were surprised to find themselves advancing in years; in addition, they were confronted by friends and injecting peers dying of liver disease related to hepatitis C as hepatitis C had never been prioritised and/or they experienced systemic barriers and discrimination in their attempt to seek hepatitis C medical care.<sup>15</sup>

Consistent with the ageing demographic of the general Australian population, the proportion of older people who inject drugs is increasing.<sup>16,17</sup> Unfortunately, the

ageing population of people who inject drugs is not reflected in the Australian National Drug Strategy 2010-15<sup>18</sup> and which, as Australian Injecting & Illicit Drug Users League notes, clearly has a youth focus and emphasises prevention and early intervention strategies.

Despite the increasing diagnoses of hepatitis C amongst Australians aged over 50 years and the high proportion of people ageing with the virus after being infected at a young age, there has been no research into the social, health and support needs of people growing older with hepatitis C. It is worth noting that aside from the AIVL report,<sup>15</sup> previous exploration of the needs of people with hepatitis C,<sup>19-22</sup> have not examined the potential impact of ageing on the delivery of services or the changing needs of people with hepatitis C as they grow older. The omission of ageing from previous needs assessments and the National Hepatitis C Strategy is significant because these are pivotal documents that direct the activities of community agencies and government policy.

# Project aim

The aim of this study was to explore the perspectives of key clinical, community and bureaucratic stakeholders on broad issues resulting from ageing among people with hepatitis C, and the challenges, if any that relate to hepatitis C and ageing in order to inform future research directions. People with hepatitis C were not specifically targeted for inclusion in this project.

## Methods

The current study used a qualitative methodology to explore the phenomenon of ageing and hepatitis C from the perspective of people working in the field of hepatitis C. A purposive recruitment strategy was used to identify key stakeholders in the hepatitis C clinical, community and government sectors. Participants were recruited through the researcher's professional network and the research organisation's (Australian Research Centre in Sex, Health and Society, La Trobe University) network. People working in the following institutions/sectors were approached to be involved in the project:

- Hepatitis Australia and its member organisations
- the Australian Injecting & Illicit Drug Users League and its member organisations
- senior clinical service providers involved in caring for people with hepatitis C (including medical specialists, GPs with a special interest in hepatitis C and hepatology nurses) in Victoria, Queensland, New South Wales and Western Australia
- public health and policy bureaucrats whose work focuses on reducing the impact of Blood Borne Viruses (BBVs)

A Victorian Government aged care policy officer was recruited given their previous contact with the research organisation for a study on people with HIV and ageing.

Data was collected through semi-structured interviews conducted either face-to-face or by the telephone. Interviews were electronically recorded for the purposes of analysis as a part of the research process. Participants were asked to provide details of their professional role and their contact with people with hepatitis C or older

Australians, and their observations about hepatitis C and ageing. In particular participants were asked:

1. Are there issues confronting people with hepatitis C as they grow older in Australia?
2. What are the challenges associated with hepatitis C and ageing for your work/organisation now, and over the next decade?
3. From your experience, what are the challenges associated with hepatitis C and ageing in the broader Australian experience?

The data was analysed using thematic analysis techniques.<sup>23</sup> The researcher listened to the electronic recordings of the interviews to become familiar with the data and identify significant themes. Extracts of the interviews were subsequently transcribed according to identification of thematic codes. The transcriptions were reviewed and the codes confirmed. The codes were subsequently organised into themes and interpreted for the purpose of developing this paper. The data was de-identified except for profession.

The study was approved the Human Research Ethics Committee at La Trobe University, Melbourne. All participants provided written informed consent prior to participation.

# Results

## Participants

In total, 22 interviews were conducted to identify key issues and challenges relating to ageing and hepatitis C in order to inform future research directions. Interviewees represent professional services including clinical (senior medical specialists (n=3), hepatology nurses (n=4) and a general practitioner (GP) with a special interest in hepatitis C (n=1)), community sector (hepatitis organisations (n=8) and drug user organisations n=2), policy and state government sector (specifically the blood borne virus sector n=3) and an ageing sector policy maker (n=1).

## Main findings

### Defining the issue of ageing in the context of hepatitis C

All of the 22 study participants identified a need for further research into hepatitis C and ageing. Three participants highlighted the ageing “baby boomer” generation as driving the current interest in identifying the specific needs of older people, and the infrastructure and resources required to address the issue broadly in the present and the future. One community worker stated:

*Australia has an ageing demographic and there are significant concerns generally about planning for the care needs of older Australians and how these services can be funded.*

Participants noted that acknowledging the significance of hepatitis C and ageing in Australia and gaining appropriate recognition will require key advocates to develop an understanding of ageing in the general Australian population. Understanding the broader context will assist in identifying the possible barriers and enablers to an effective public health response for hepatitis C and ageing. One bureaucrat described the need for a significant amount of work to recognise hepatitis C and ageing as a public health issue in Australia;

*Hep C and ageing has not been explored ... hep C is still considered a young person's condition, even though people are hitting their 50's and 60's with advanced disease...*

While most participants believed that issues around hepatitis C and ageing were important, the level of contact with older people living with hepatitis C was often minimal. Those working in the community sector indicated they had very limited contact with older people with hepatitis C. Clinicians reported having contact with a small proportion of the ageing cohort given the urgent need for management of hepatitis C-related morbidity. The lack of contact with older people with hepatitis C is a significant barrier to understanding the care and support needs of older people with hepatitis C. As highlighted by a community worker:

*Anecdotally we know that many people diagnosed in the 1990s were given messages on diagnosis that would be considered highly inappropriate now, such as 'go home, don't worry about it, but don't share your toothbrush.' It is therefore possible that there is a large cohort of people diagnosed with hepatitis C who are 20 years older than when they were diagnosed, who are not paying attention to their liver health.*

Participants expressed an overwhelming sense of inevitability regarding hepatitis C and ageing; based on the epidemiological data previously discussed, specifically the distribution of hepatitis C infection that indicates that the burden of liver disease attributable to hepatitis C is highest amongst people over 50 years. A community worker who works with people who inject drugs highlighted the impact of the delay in responding to hepatitis C and ageing as a predictable issue:

*Ageing has to be a significant component of the hepatitis C story considering the 20-30 year timeframe to symptoms. I'm dismayed that this wasn't anticipated ... until now when it's hitting us in the face ... I have several friends who have died ... older people with hep C.*

Many participants had considered hepatitis C and ageing in the course of their work, but when they were asked to define "ageing" in the context of hepatitis C, participants had several responses. Generally, ageing in the context of hepatitis C was loosely described as older than 55 years; even though the Commonwealth Government

definition of ageing refers to people over the age of 65 years. However, as one medical practitioner identified:

*The Commonwealth defines [ageing] as 65 years +, which is all very well; but consider people with a chronic health condition and the age goes down ... 40s is ageing for some people with chronic diseases.*

This comment about ageing beginning at a younger age was acknowledged by the Australian Injecting and Illicit Drug Users League in their peer-based consultation<sup>15</sup> which concluded that ageing amongst people who inject drugs commenced at the age of 40 years.

*Forty years was the age that we saw things starting to change for people – getting older had an impact ... 40 years was a point where [clinical] interventions would have an impact before it was too late and the ageing process had taken a hold.*

The fact there is a disparity of more than 20 years between the Australian Injecting and Illicit Drug Users League and the Commonwealth Government's consensus on "ageing" was highlighted by participants as demonstrating the potentially unique and contextual circumstances surrounding hepatitis C and ageing. There was agreement on the need for evidence to inform the development of a strategic response to hepatitis C and ageing in Australia. The dearth of evidence means that the needs of older people with hepatitis C remain unrecognised.

### **What's the issue with hepatitis C and ageing?**

All participants identified progression of liver disease as the most obvious concern associated with hepatitis C and ageing. Participants articulated a link between hepatitis C, ageing, advanced liver disease and liver cancer regardless of their professional background. Another common thread which emerged in several of the interviews related to the lack of evidence available to guide the policy and research agenda and as a consequence it was not clear whether the focus should be on ageing and hepatitis C, or the experiences of people with advanced liver disease, or people who have been living long term with hepatitis C (the effect of duration of infection). Each perspective addresses a slightly different population, and emphasises a different subset of questions regarding an individual's needs. The inter-relatedness of each of the

potential causes of the issues associated with hepatitis C and ageing was articulated by one community worker:

*Anyone over 40 years could have had hep C for 20+ years and be at increased risk from the complications associated with duration of infection. As we know, progression of liver disease starts to escalate dramatically after two decades of living with hepatitis C.*

Several participants highlighted the significant clinical and social evidence supporting the effect of HIV infection as a precipitant to advanced ageing and suggested there needed to be similar research conducted to investigate whether hepatitis C had a similar effect. Although no evidence currently exists, several participants highlighted the impact of extrahepatic manifestations of hepatitis C on the development of significant co-morbidities, which could lead to accelerated ageing. One clinician stated:

*I get the feeling there may be some issues that are specific to older people with hepatitis C ... this warrants further investigation.*

This perspective merits the question whether “age” is a proxy for “severity of liver disease” or whether there are specific-age related issues associated with mild liver disease. It appears clear from insights provided by clinical participants that there are numerous risk factors and co-morbidities that accompany older people with or without hepatitis C. The likelihood of developing co-morbidities such as diabetes, cancer, hypertension and high cholesterol increases as people age. In turn, both the co-morbidities associated with ageing generally and those associated with hepatitis C complicate the management of hepatitis C. Several clinicians highlighted the complexity of treating older people for hepatitis C, with one stating:

*The reality is that once you get to “that age” you’re more likely to have hypertension and cardiac issues etc, and the [hepatitis C] medications are not as well tolerated, so we are trying to slip in hep C treatment before they hit the 60+ age group.*

Three clinicians were mindful that treating older people for hepatitis C may be a risky proposition; as expressed by one participant:

*We're just really mindful that by treating older people with hepatitis C we could set off a chain reaction of health issues that we may not be able to reign back in.*

Another participant identified that older people with hepatitis C were often more desperate for clinical management because they realised that they may have missed their chance to be treated and potentially be cured of hepatitis C:

*There's an increased sense of desperation for people in their 60's, that if they don't do something about [hepatitis C] now ... I think it's related to mortality ... 10 years ago if you had a 65 year old come in wanting treatment with combination therapy ... you wouldn't treat them ... you wouldn't touch someone over the age of 65 years! But ... we've just treated a 72 year old, with some trepidation, but they didn't have a cardiac history or any other co-morbidities.*

While recognising that treating hepatitis C in older people was more complex due to co-morbidities, there was equal recognition that older people experience other psychological effects of living with hepatitis C, which may not be expressed physically. A hepatology nurse stated:

*Older patients with hepatitis C are getting more tired. My patients, who are over 50 and 60 years, complain of feeling more tired and more "down". They've often lived with the disease for longer, emotionally they're more affected. The stress and strain of living with hepatitis C has taken its toll ... Most of them have been diagnosed for a while, but they've only recently prioritised their hepatitis C.*

The changing clinical environment has led to significant developments in the treatment and management of hepatitis C. Many patients in hepatitis/liver clinics across Australia have been advised to wait for the new treatments which promise high response rates with fewer side effects. In particular, patients with co-morbidities that may complicate the administration of the current treatment regimens are being advised to wait for the "better treatment options". One clinician described their concern that reluctance to treat older people with hepatitis C has created a cohort of patients who may never have the opportunity to clear the virus:

*Once you reach that age ... probably 70-75 years there are multiple system changes which will affect the long standing, underlying liver disease ... and that's when we'll be left saying – it's too late to give them the present drugs, it's too late for a transplant and we really missed the boat ... whether there will be a boat of guilty clinicians who perhaps think they should've treated people earlier, and angry patients who say "for goodness sake, you knew I had hep C what's wrong with you?"*

One community worker reinforced the clinician's concern:

*Friends of mine have left their run at [hepatitis C] treatment too late, and are now asking how come no one told me 5-10 years ago that this was my last chance to be treated? They've been denied treatment for reasons that have been shown to be irrelevant such as they're still using or they're older ... they've lost their chance of clearing the virus.*

Finally, there was a shared view amongst clinicians that the new interferon-free treatments regimes will solve the problem of hepatitis C in the future. One participant stated:

*I hope the issues associated with hep C and ageing become a heck of a lot less over the next decade, if we get what we're being promised – all oral agents, 3 month course, 100% success rate. We could wipe out the hep C discussion all together in people with advanced liver disease, even those people with advanced liver disease that is too advanced to treat with Peg [interferon] and Ribavirin now.*

However, this belief was challenged by several community workers, who acknowledged that many of the issues associated with living with hepatitis C are not solely related to clinical issues. For example, the isolation and marginalisation experienced by many people with hepatitis C that often results in late presentation to clinical services and the risk that perceived or actual stigma and discrimination creates barriers to accessing support services. One participant explained:

*I find the attitude that the "drugs are going to fix everything" in hepatitis C so interesting ... I do acknowledge the importance of pharmaceutical developments and what might happen when interferon is no longer*

*required, but quite frankly we have existing problems that are not just about the drugs (treatments).*

### **Ageing and hepatitis C amongst people who inject drugs**

Participants acknowledged that there are significant issues for people with hepatitis C as they grow older because of the association with injecting drug use. Many of these issues are articulated in AIVL's report into older injecting opioid users in Australia.<sup>15</sup> A community worker elaborated:

*[Growing old is] hard for people with hepatitis C who have other comorbidities when everything is ok in your life. When you add to that significant levels of poverty, unemployment and significant mental health issues, and huge amounts of stigma and discrimination ... that's the picture for people who inject drugs. We could see that [ageing and hepatitis C] was an issue that needed to be put on the agenda and some very specific measures taken to address it now rather than wait until we've got bigger problems on our hands.*

Participants who work with people who inject drugs were keen that a range of issues were explored in relation to hepatitis C and ageing, and felt that no single research organisation would be able to respond to the breadth of questions around ageing that need to be addressed. One community worker described their preference for a coordinated research response.

*If research into hepatitis C and ageing can progress, it would be great if the natural history of ageing and hepatitis C could be identified and explored. Then we could answer the question – does hepatitis C accelerate the ageing process? Combine this with a better social understanding of the impact of hepatitis C, ageing and the impact of the issues associated with drug use such as poverty, homelessness and stigma.*

Several community workers discussed that people with hepatitis C were dying prematurely as a result of hepatitis C, even compared to a couple of years ago. Late presentation to clinical services amongst people who inject drugs living with hepatitis C was highlighted as a concern and articulated by a community worker:

*The reasons for late presentation [to clinical services] needs to be addressed ... obviously stigma and discrimination are significant issues for PWID (people who inject drugs); those daily, attitudinal bits and pieces are really beginning to bite and it prevents people from asking for help.*

There was general concern amongst participants that older people who inject drugs with hepatitis C are a hidden and isolated group. As a community worker explained, drug use in Australia has a youth focus and is associated with the risk taking period associated with being young:

*The concept of an older drug user just doesn't sit well within the scheme of things; services are largely constructed around the generalised stereotype of a younger rather than older people.*

One participant who was living with hepatitis C articulated the youth focus of injecting drug use:

*It's ok to think you were a bit wild when you were young but somehow admitting to once being an IV drug user when you are much older gets more difficult. For example, telling the grandkids that their grandmother has an IV drug use related illness is tricky.*

The impact of harm reduction strategies such as opioid replacement therapy means that people who inject drugs are now reaching old age where previously they may have died at a younger age,<sup>24</sup> and highlights the inadequacy of the current response to ageing for minority groups such as people who inject drugs.

### **Where does hepatitis C and ageing “fit” in the broader Australian context?**

Considering that older people with hepatitis C are not identified as a priority population or their needs discussed in the National Hepatitis C Strategy, it is not surprising that hepatitis C and ageing is not identified as a priority on the national or state health agenda. An aged care policy worker clearly articulated:

*Hepatitis C is not on the [state] Department of Health's agenda regarding ageing or growing older. However, HIV is on the agenda, particularly from the perspective of the long term side effects of being on HAART.*

When asked of the most effective way of raising the profile of hepatitis C and ageing, this participant suggested that:

*Hepatitis C needed to be framed as a chronic disease which has physical, social and emotional effects ... in contrast to focusing on the clinical perspective.*

While there has been a shift towards framing hepatitis C as a chronic disease in the programmatic response of the hepatitis C community sector in Australia, the literature exploring hepatitis C and ageing remains firmly entrenched in a clinical framework. It is also apparent that there is little research evidence to guide a response.

### **Aged-care services and hepatitis C**

The lack of awareness of BBVs, specifically hepatitis C, amongst aged care services staff was repeatedly expressed by participants working in the community sector, and by the workers responsible for workforce development as a significant concern for older people with hepatitis C. One participant explained:

*A lot of aged care staff are uneducated about BBVs, they often don't want to discriminate but do ... aged care staff are often not as well educated as hospital staff and these types of environments often breed breaches of confidentiality, discrimination and lack of privacy.*

Community based staff from hepatitis organisations explained their struggle to access home care services for people with hepatitis C, particularly while people are on antiviral treatment and experiencing debilitating side effects. With this experience in mind, several participants expressed concern that access to home care services for people with advanced liver disease or the complications of hepatitis C may also be limited.

While older people are being supported by government policy to stay at home, older people with hepatitis C are reported to experience isolation due to family breakdown related to past injecting drug use<sup>15</sup> and require support that is external to their family network. As explained by a community worker:

*We're starting to get phone calls regarding aged care services – sometimes it's the sibling or the parent, sometimes it's the consumer themselves,*

*asking are there any aged care services who know about people of this age group who inject drugs or are on pharmacotherapies ... we haven't even begun to do that type of scoping ... I suspect they don't exist.*

In terms of who is caring for older people with hepatitis C, one clinician acknowledged that *"I don't think we've got great systems in place to look after older patients in the liver clinic"*. Most participants identified general practitioners as the default carer of older people because no other profession was positioned to implement a holistic approach. A senior bureaucrat added:

*There is a lack of medical generalists, so the doctors are all siloed and issues such as hep C and ageing are slipping through the cracks. The GP becomes critical in this setting, because they are the only health professional who cares for the patient "holistically," not just systems focused.*

In addition, one specialist clinician acknowledged that:

*Hepatologists and infectious diseases doctors are not as aware of the needs of older patients with hepatitis C. Once you become a specialist, your general medical and geriatrics thought processes get turned off; and I don't think we've got many clinicians in the hep C treatment arena who are geared to thinking about the issues of old age.*

The lack of "clinical responsibility" for older patients with hepatitis C adds to the complexity of hepatitis C and ageing in Australia.

# Conclusions

This study aimed to ascertain the extent to which clinical, community and bureaucratic stakeholders identify hepatitis C and ageing as an issue for their work. Universally, hepatitis C and ageing was identified as an important issue requiring further investigation.

Hepatitis C and ageing was considered by participants as an important area for future social, clinical and epidemiological research in Australia. However, the significance of hepatitis C and ageing as a public health issue has not been acknowledged by the Australian government and is not an issue for the national health agenda. There is a clear need for advocacy on hepatitis C and ageing however, there is inadequate data to support such advocacy. Therefore, the need for epidemiological, clinical and social research on hepatitis C and ageing was viewed as a matter of urgency.

Participants were mindful of the very limited contact with older people with hepatitis C, and were concerned they had a limited understanding of their needs. The gaps in knowledge and the foreseeable implications of ageing with chronic liver disease also highlighted the urgency to understand the issue in greater detail.

It is worth noting that previous research exploring the needs of people with hepatitis C in Australia<sup>19-22</sup> and the various iterations of the National Hepatitis C Strategy<sup>11</sup> have not specifically acknowledged the impact of ageing. However in 2010, the Australian Injecting and Illicit Drug Users League identified the need for greater understanding of the impact of ageing on people who inject drugs, a significant proportion of whom are also living with hepatitis C. This pivotal report highlights the issues of social isolation, stigma and discrimination and other barriers to accessing clinical and community services particularly confronting older people who inject drugs. An important finding of that report is the deleterious effect of the youth focus of drug policy in Australia and its impact on further alienating older people who inject drugs.

While the current study focused on understanding the perceptions of hepatitis C and ageing from the perspective of key community, clinical and bureaucratic stakeholders, it is strongly acknowledged that the insight of older people living with hepatitis C is needed to inform a broader and more insightful understanding of the issue.

An issue that will require further clarification in future research is distinguishing between the impact of ageing and duration of infection. There was much discussion amongst participants about age as a proxy for duration of infection and severity of liver disease, and whether there were issues associated with hepatitis C and ageing in the setting of mild liver disease. Inclusion of older people with hepatitis C in future clinical research will assist in addressing this issue.

A limitation of this study is the lack of involvement of stakeholders working in the aged care sector. While significant effort was made to engage with aged care policy workers from both Victoria and national non-government and government sectors, participants were difficult to recruit due to lack of interest or expertise in hepatitis C. To develop relationships for conducting future research, work needs to be done by the hepatitis C sector with the aged care sector to ensure that hepatitis C is understood as a chronic disease, rather than a clinical or communicable disease. Reframing hepatitis C as a chronic disease with physical, social and emotional effects will align it with existing Commonwealth health policy, and thus encourage and support meaningful cross-sectoral engagement between the ageing and BBV sectors.

Most importantly there is no need to recreate existing services specifically for people with hepatitis C. Instead it is critical to understand the context in which older people with hepatitis C are living and the support networks and strategies that already exist in order to be able to connect them.

The lack of understanding and potential for hepatitis C-related stigma and discrimination amongst workers in residential aged care services towards older people with hepatitis C was repeatedly raised as a concern. However, the reality is that a very small proportion of older people (less than five percent) live in residential aged care services. While there is the need for hepatitis C workforce development for staff of residential aged care services, this cannot be to the detriment of developing the capacity of home and community care services. As the Australian population ages, greater emphasis will be placed on keeping older people at home.

## Recommendations

1. A national hepatitis C needs assessment should be conducted to specifically explore the needs of older people with hepatitis C and develop an understanding of the challenges at the individual, interpersonal, family, community and service level.
2. Future research is needed to explore how best to support GPs and the aged care sector workforce to better manage older people with hepatitis C.
3. Fundamentally, research needs to address whether “age” is a proxy for “severity of liver disease” or whether there are specific-aged related issues associated with hepatitis C-related mild liver disease.
4. Epidemiological research is needed to quantify the burden of hepatitis C in older Australians and identify the percentage of older people with hepatitis C who currently access clinical services and antiviral treatment.
5. Advocacy for acknowledgement of hepatitis C and ageing as a significant national public health issue needs to occur. A flow on effect of such advocacy should be the development of national affiliations between the hepatitis C and aged care sectors, to allow for collaborative planning and service delivery, acknowledging the needs of older people with hepatitis C.

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