

## **Section 11**

### **Discussion**

## Introduction

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

This PEEK study in HER2 hepatitis D includes 16 people diagnosed with hepatitis D throughout Australia.

Following a PubMed search (March 6, 2023) very few studies of the experience of people with hepatitis D were found. As people with hepatitis D are co-infected with hepatitis B, studies of the experience of people with hepatitis B are included in this discussion.

## Background

Hepatitis D is a viral hepatitis that can only replicate with Hepatitis B. Hepatitis D infection may occur simultaneously with hepatitis B (coinfection), or can occur in chronic Hepatitis b (superinfection)<sup>1</sup>. Coinfection is often acute and will clear within 6 months, however, there is risk of acute liver failure<sup>2</sup>. Superinfection is the most common form of hepatitis, and has a higher risk of cirrhosis and liver cancer<sup>2-4</sup>.

Hepatitis D is transmitted through broken skin or blood, transmission can occur from mother to child but it is rare<sup>5</sup>. The majority of hepatitis D patients are asymptomatic, symptoms can include fever, abdominal pain, nausea, vomiting, jaundice, confusion, bruising, or bleeding, loss of appetite, dark urine, and pale-coloured stools<sup>5,6</sup>.

Hepatitis is more common in the Middle East, West and Central Africa, Amazonian river basin, Mongolia, Romania, Russia, Pakistan, Georgia, and Turkey<sup>7</sup>.

In Australia 2016, 61 cases of hepatitis D were notified, with an average of 48 cases annually in the period 2011-2015, most cases were reported from New South Wales, Victoria, and Queensland<sup>8</sup>. In Australia, hepatitis D is more common in people born in Vietnam, Sudan, and Afghanistan, and there is a higher risk for

anyone who has ever been in prison<sup>9</sup>. More males than females have hepatitis D in Australia, at a rate of 2:1<sup>8</sup>.

## Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have hepatitis D.

In this PEEK study, the proportions of participants that lived in areas with non-school qualification qualifications (certificate, diploma or degree), and the proportion in paid employment were all similar to that of Australia. There were more that lived in major cities, and in areas with higher socioeconomic status compared to the Australian population<sup>10,11</sup> There were no participants from the Northern Territory, or Canberra, or Tasmania, and there were a higher proportion of participants from Victoria, and similar proportions from New South Wales, Queensland, South Australia and Western Australia compared to the proportion that live in each state<sup>12</sup>.

**Table 12.1: Demographics**

Demographic	Australia %	Hepatitis D PEEK %
Live in major cities	71	81
Non-school qualification	65	69
Higher socioeconomic status (7 to 10 deciles)	40	88
Employment (aged 15 to 64)	74	75
New South Wales	32	31
Victoria	26	38
Queensland	20	19
South Australia	7	6
Western Australia	10	6
Tasmania	2	0
Northern Territory	1	0
Australian Capital Territory	2	0

## Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with hepatitis D participants.

## Other health conditions

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition<sup>13</sup>. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%),

asthma (11%), diabetes mellitus (5%), heart, stroke and vascular disease (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)<sup>13</sup>. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition<sup>13</sup>.

In this PEEK study, participants had higher levels of anxiety (50% compared to 13%), depression (50% compared to 10%), arthritis (29% compared to 15%), asthma (21% compared to 11%), COPD 14% compared to 3%), and cancer (14% compared to 2%) compared to the Australian population.

In this PEEK study, 86% of participants had comorbidities, most commonly anxiety and depression. Another study described lower rates of 25% with comorbidities<sup>14</sup>, the difference may be due to the types of comorbidities included. Other hepatitis B studies described listed liver disease, anxiety, and depression as common comorbidities<sup>14-17</sup>. In this PEEK study, 50% had depression, 50% had anxiety, and 50% had other liver disease.

### Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual<sup>18</sup>. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function<sup>18</sup>.

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the hepatitis D community in this PEEK study compares with the Australian population<sup>19</sup>. The hepatitis D PEEK participants on average had considerably lower scores for all SF36 domains with the exception on SF36 Pain. Other studies of participants with hepatitis B have also described worse health-related quality of life compared to the general population<sup>15,20,21</sup>.

While 75% of people in this PEEK study were in paid employment, physical health problems interfered with daily activities including work.

There was one study that described health-related quality of life for people with hepatitis D, it described

that health related quality of life was lower for the functional well-being, worry, and activity impairment domains compared to those with hepatitis B<sup>22</sup>. This is consistent with the current PEEK study where participants had limitations in function due to physical health.

In other studies of people with hepatitis B, comorbidities, in particular anxiety, depression and liver disease were negatively associated with health-related quality of life<sup>15,16</sup>. The high rates of comorbidities in this PEEK study may contribute to reduced quality of life. Other studies reported that being male, having current life stressors, unemployment, low social support, and undergoing current treatment were negatively associated with health related quality of life for people with hepatitis B<sup>21,23-25</sup>. Health quality of life for people with hepatitis B improved following treatment<sup>21,25-27</sup>, and being male, and younger was positively associated with health-related quality of life<sup>21,23</sup>.

### Key points

- High rates of anxiety and depression
- Poor quality of life compared to general population

### Risks and Symptoms

*So what happened to me was I felt very unwell. I was working full time and I thought, you know, my aching joints, my sleepless nights, my brain fog, all those things were attributed to the fact that I was getting older. I was finding full time work more hard and I had we had pains in the tummy as well and anyway I went to the doctor and he suggested being tested based on my history. Participant 010\_2023AUHDV*

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

More than half of the participants in this study were asymptomatic before diagnosis. For those that had symptoms before diagnosis, the most common symptoms were fatigue, abdominal pain, muscle or joint pain, jaundice, nausea vomiting, fever, bloating, and changes to bowel movements. Similarly for studies

of people with hepatitis B, other studies describe participants being asymptomatic, having pain, fatigue, jaundice, bloating, irritability poor appetite, nausea, flu like symptoms, and being generally unwell<sup>14,28</sup>.

### Screening and diagnosis

Hepatitis D is diagnosed from a blood test, where high levels of anti-HDV immunoglobulin G (IgG) and immunoglobulin M (IgM)<sup>5</sup>. Hepatitis B is diagnosed with a blood test, there are three serological markers, the hepatitis B surface antigen (HBsAg) which indicated active infection, , antibodies to HBsAg (anti-HBs) which show resolved infection or successful vaccination, and antibodies to hepatitis B core protein (anti-HBc) which indicates past or present infection<sup>29</sup>. HBV DNA testing, liver function tests, and assessment of liver fibrosis is recommended for people with chronic hepatitis B to determine eligibility for antiviral therapy<sup>29</sup>.

In this PEEK study, almost all participants recalled having blood tests for hepatitis B and D. Less than half of the participants recalled having liver function test of assessment of fibrosis.

In this PEEK study for those that had symptoms before diagnosis, two thirds had a diagnosis within a year of noticing symptoms. Almost half of the participants had a diagnosis within 2 weeks if having a diagnostic test.

### Understanding and knowledge

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings<sup>30,31</sup>. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis<sup>32,33</sup> others, especially those who have symptoms for long periods before diagnosis, will gain information in terms of how to live with or adapt to symptoms they experience<sup>34</sup>. For some people, the first time they have heard of their chronic condition is when they are diagnosed<sup>33</sup>. At the time of diagnosis, it may be useful for the healthcare professional to talk about how much a patient knows about a condition so that appropriate information can be given, and correct misconceptions<sup>33</sup>.

In this PEEK study, 75% of participants had no or little knowledge about hepatitis D when they were diagnosed. In addition, a quarter of participants were uncertain about their prognosis.

### Biomarkers or genetic markers

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course. HBV DNA testing, liver function tests, and assessment of liver fibrosis is recommended for people with chronic hepatitis B to determine eligibility for antiviral therapy<sup>29</sup>

More than half of the participants in this PEEK study did not have any discussions about biomarkers or genetic markers, and almost a third described having these tests.

### Support at diagnosis

Very few participants in this PEEK study described having enough support at diagnosis (14%), the same number described having some support but not enough (14%), but the majority of participants described having no support at diagnosis. A study of people with hepatitis B described the being shocked when diagnosed, having a sense of loss of hope, and feelings of anxiety and depression<sup>28</sup>, indicating a need for support at diagnosis.

Half of the participants in this PEEK study described having no liver complications from hepatitis D, 36 % had cirrhosis of the liver, 14% had fibrosis of the liver, 7% had liver cancer, and 7% had fatty liver. The majority of participants in this study (64%) were offered regular liver checks

### Information at diagnosis

*Very little. Very little at all. And I'd have to say, even at that point of diagnosis, they didn't really take the time to explain it to me and how it was all interrelated. It was only kind of subsequently in conversations...that I understood it had something to do with my liver.*

*Participant 011\_2023AUHDV*

In this PEEK study, the majority of participants either had no information or not enough information about hepatitis D when they were diagnosed (79%), this is notable given that the study population had little or no knowledge of hepatitis D at diagnosis. In another study, people with hepatitis D described the types of information they needed at diagnosis, the topics included how to interpret test results, general information, treatment and management, and information about infection transmission<sup>35</sup>.

## Key points

- Asymptomatic at diagnosis
- Lack of support at diagnosis
- Not enough information at diagnosis

## Decision making

The decision-making process in healthcare is an important component in care of chronic or serious illness<sup>36</sup>. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare<sup>37,38</sup>, highlighting the importance of healthcare professional communication. In addition, the role of family members in decision making is important, with many making decisions following consultation with family<sup>39</sup>.

## Goals of treatment and decision-making

*My own concern is having cancer in the future. The other things I think is is treatable but not cancer is my only concern. Participant 005\_2023AUHDV*

Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous consultations and results<sup>40,41</sup>. Half of the participants in this PEEK study were presented with one treatment option, however, very few described taking part in treatment discussions. Important factors in decision making for the participants in this PEEK study were their ability to follow treatments, efficacy of treatment, side effects and costs. Likewise, in a study of people with hepatitis B, how treatments are administered, efficacy, side effects and costs, as well as impact on quality of life were important factors to consider when making treatment decisions<sup>42</sup>. The most common treatment goal in this PEEK study were to maintain their condition, and for quality of life or return to normalcy. Participants in this PEEK study described fatigue as the most important symptom to control for quality of life, followed by liver cirrhosis or fibrosis

## Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having hepatitis D are collected.

## Access to health professionals

The main providers of treatment for hepatitis B for participants in this PEEK study were general practitioners (GP) and hepatologists. The majority could access their main provider of care for hepatitis D within 60 minutes (72%), and the majority found it either easy or very easy to get appointments (64%). The majority had access to either a gastroenterologist or a hepatologist (70%), and access to a GP (86%). Few participants had access to a hepatology nurse (36%).

## Affordability of healthcare

Almost half of the Australian population have private health insurance with hospital cover<sup>43</sup>. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from about 8% to 14%<sup>43</sup>. In this PEEK study, a similar proportion had private health insurance compared to the Australian population.

The majority of participants in this PEEK study described that there was some cost burden to them from having hepatitis D, and for approximately 40% this was at least a moderate burden. Costs were from treatments, taking time off work, travel to and from health appointments. Nearly half the participants in this study had either reduced the number of hours they worked or they had to quit their job adding to their cost burden. In another study, people with hepatitis B described the costs associated with their condition from loss of employment, cost of treatments, cost of health insurance and that at times other basic necessities such as food and housing take priority<sup>23,27,44,45</sup>.

## Treatment and management

Hepatitis D is treated with pegylated interferon alpha for 48 weeks, treatment should continue regardless of response rate.<sup>5</sup> There is a low response rate to the treatment, however, it is associated with a lower likelihood of disease progression treatment should continue regardless of symptoms<sup>5</sup>. There is no vaccine available for hepatitis D, however, hepatitis B vaccination protects against hepatitis D infection<sup>5</sup>.

The majority of participants in this PEEK study had drug treatments (93%) for hepatitis D, 79% of participants had pegylated interferon alpha. On average, quality of life from Pegylated interferon alpha was in the 'life was distressing' range, and was found to be ineffective.

Other drug treatments used by participants in this PEEK study included Entecavir (29%), Ribavirin (29%), Tenofovir (29%), Glecaprevir/pibrentasvir (7%), and Sofosbuvir/Velpatasvir (7%)

To highlight unmet needs, participants in this PEEK study described what they would like to see in future treatments. They described that they would like to have more choice, transparency and discussions in relation to treatment options, treatments that are less invasive, and treatments that are more affordable.

### Allied health

Allied health is important to manage the physical, emotional, practical and financial consequences of hepatitis D. Half of the participants in this PEEK study used allied health services, most commonly psychologists (29%), dieticians (21%), and social worker (14%).

### Lifestyle changes

Many chronic diseases share the modifiable risk factors of poor diet, little exercise, smoking, and excessive alcohol consumption. In this PEEK study, approximately 60% made lifestyle changes, most commonly diet changes (50%), and reducing or quitting alcohol (43%). Quality of life for both these changes were in the life was average range, and diet changes were rated moderately effective and reducing alcohol was rated very effective.

### Complementary therapies

Complementary therapies include taking supplements, mindfulness and relaxation techniques, massage therapy and acupuncture and many others. In this PEEK study, approximately a third of participants used complementary therapies, most commonly massage therapy, and mindfulness and meditation.

### Clinical Trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects.

A search of the Australian New Zealand Clinical Trials Registry was conducted on July 25 2023. The search included any study that included participants with

hepatitis D in the inclusion criteria, was conducted in Australia. A single study was identified that was not yet open to recruitment. This study is a randomised trial evaluating a drug treatment, has a target of 32 participants, and will have sites in New South Wales and Victoria. A search of clinicaltrials.gov was conducted on the same day with the same search criteria, one study was identified, a randomised trial evaluating a drug treatment, 79 participants had enrolled and the trial was terminated in 2016. It was an international trial with sites in New South Wales, South Australia, Victoria, and Western Australia.

### Patient treatment preferences

*Well, I'm not that kind of person. If I get treatment and I'm told to take it from the beginning to the end, I take it until it's finished. I never, I never stop unless it's giving me a severe side effect which really makes me ill, then I take it till it's finished.*  
*Participant 010\_2023AUHDV*

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance.<sup>46-48</sup> Patient preferences and priorities vary across different health issues, preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle<sup>46,49</sup>.

To help inform patient preferences in the hepatitis D community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. Mild side effects were described by providing examples, or as side effects that are self managed or do not interfere with life. Examples of specific mild side effects included headaches, aches and pains, emotional impact, skin rashes, dizziness, and nausea. In a similar way, participants describe severe side effects, broadly as those that impact every day life, or using the examples of pain, emotional impact, fatigue, and allergic reactions. There is some similarity the descriptions and examples used to describe both mild and severe side effects, indicating the importance of describing the intensity and impact of expected side effects of treatment.

### Self-management

*I think it needs to be a combination of things, the online is a very good option and search option for people initially and especially depending if there's*

*barriers with English and other things. Yeah, that is one good option, but I think the conversation. Participant 004\_2023AUHDV*

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving<sup>50</sup>. Components of self-management include information, activation and collaboration<sup>50</sup>.

Information is a key component of health self-management<sup>51,52</sup>. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management<sup>51,52</sup>.

In this PEEK study participants were most commonly given information about treatment options, and disease management, these were also the most commonly searched for topics. In another study, similar to this PEEK study, participants with hepatitis D had searched for how to interpret test results, , treatment and management, psychological/ social support, disease cause, , complementary therapies, and lifestyle modifications, in addition they searched for relationship HDV to HBV, risk of liver cancer, and symptoms<sup>35</sup>.

In a study of people with hepatitis B, participants had searched for information about treatment and management, prevention, vaccine efficacy, diagnosis, spread and protecting others, and interpreting test results<sup>44</sup>

Participants in this PEEK study got most of their information from their doctor or from the internet. They described that there wasn't any information that was not helpful, but noted a lack of new information was a problem. Hearing about what to expect and other peoples experiences were helpful.

To highlight unmet needs, participants in this PEEK study described what they would like to see in future information. In terms of access, they described wanting information in a variety of formats, including the ability to talk to a healthcare professional, they wanted information that was easy to find and easier to understand, including in their native language. The Volume 6 (2023), Issue 3: PEEK Study in Hepatitis D

topics they wanted more information about were emotional health, disease trajectory and what to expect, information about transmission, where to find support and information to support carers. Additionally, they wanted information to raise community awareness. In another study, people with hepatitis B had a lack of understanding of their condition, treatment and management<sup>45</sup>.

*Prefer. I actually prefer to be able to sit and talk with the doctors and nurses and that and then secondary to that would be information booklets that you can take away. But generally I'll just have the conversation and that's. That's enough for me to get what I feel I need to know. Participant 007\_2023AUHDV*

### **Activation (skills and knowledge)**

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire<sup>53</sup>. Participants had in this PEEK study had good knowledge about their condition and treatments, a good ability to manage the effects of their health condition, good ability to adhere to treatments and communicate with healthcare professionals, and good recognition and management of symptoms.

Participants in this PEEK study described how long they would adhere to a treatment, most commonly they described adhering to their treatment as per the advice of their doctor. Others needed to see evidence that treatment is working and some described only adhering to treatments if side effects were tolerable. Consistent with this, a number of participants described that they needed to see a reduction of physical signs and symptoms or evidence of stable disease to know that a treatment is working,

## Communication and collaboration

*Yeah, I'm happy. Actually, I am happy. It was very just to interpret my results because what I do is I do the my blood test and my liver thing before I got there, before I got there. So when I got there, they just interpret my result that I know this result, they're all good. This is your liver stuff is all good or good or good or good? How are you feeling? Then I'll just say, yeah, I'm still OK. I'm OK really. That's it. I'll see you next year. That's all. Participant 001\_2023AUHDV*

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support<sup>51,52</sup> Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction<sup>54-57</sup>.

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making<sup>58</sup>.

Building a relationship with patient, families and support networks is fundamental to establishing good communication<sup>58</sup>. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding<sup>58</sup>. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands<sup>58</sup>. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources<sup>58</sup>. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Patient understanding of their condition and ability to seek care when needed was improved when information was delivered in a two-way exchange.<sup>59,60</sup>

Communication and collaboration with healthcare professionals was measured in this PEEK study by the

Care Coordination questionnaire<sup>61</sup>. Participants in this PEEK study had moderate communication with healthcare professionals, good navigation of the healthcare system, they rated their care coordination as average, and they participants rated their quality of care as average. This is consistent with the communication descriptions in the structured interviews, where most described having poor communication at least some of the time. Communication was described as poor due to dismissive conversations, and limited time in appointments. For those describing good communication, this was due to holistic, two-way and supportive conversations.

To highlight unmet needs, participants in this PEEK study described what they would like to see in future communication. Participants described wanting more time to meet with healthcare professionals, and the need for communication to be transparent and forthcoming. They wanted to be listened to, and to be treated with empathy. Additionally, they wanted communication to raise awareness.

*Yeah, those two times where or maybe two or three times where the doctor and a couple of or couple of doctors and a couple of nurses were a bit judgmental about my past. So I just felt a bit vulnerable at that time, but I just spoke up so that was all good. Participant 010\_2023AUHDV*

## Care and support

In this PEEK study, participants described a lack of formal support and difficulty finding or accessing support. Where participants did have support this was from peer support, charities, community or religious groups, the hospital of clinical setting or in the form of financial support. In a study of people with hepatitis B, people described the need for support to adhere to the therapy<sup>26</sup>

To highlight unmet needs, participants in this PEEK study described what they would like to see in future care and support. They described wanting more access to support services in general, and for practical support. In terms of medical support they would like to have specialist clinics or services where they can talk to professionals, a multidisciplinary and coordinated approach, and access to health professionals with a better knowledge of the condition. In terms of emotional support they would like access to peer support, support groups and online forums, and for care to be more holistic including emotional health.



### Key points

- Lack of formal support
- Quality of care and care coordination are average
- Poor communication with healthcare professionals

### Anxiety associated with condition

*Yeah, yeah, post post treatment there's. And I think this is true for the current HDV treatments as well. But there's this period of where you're waiting to find out results. Participant 011\_2023AUHDV*

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease<sup>62</sup>.

In this PEEK study, anxiety associated with hepatitis D was measured by the fear of progression questionnaire<sup>63</sup>. Participants experienced a moderate amount of anxiety in relation to their condition. In other studies, people with hepatitis D had more fear and anxiety related to disease compared to those with hepatitis B<sup>22</sup>. People with hepatitis D were worried and shocked by diagnosis, and worried about how the condition will progress and their life expectancy<sup>35</sup>

In another study, people with Hepatitis B, participants were worried at the time of diagnosis, they were anxious about treatments, complications and dying, and about who will take care of them if sick, who will take care of family<sup>28</sup>.

In this PEEK study, participants were most worried about progression, medical appointments and treatments, symptoms and side effects, family becoming infected, what will happen to their family if anything happens to them, and not being able to work or pursue hobbies.

### Quality of life

Participants in this PEEK study described a negative impact on quality of life from having hepatitis D, this was mostly from emotional strain on themselves on their family, reduced social interaction, and from stigma and discrimination experienced. This is similar to another study where people with hepatitis B

described social isolation, stigma and shame in addition to feelings of hopelessness, fear of no romantic relationships and a fear of death having a negative impact on quality of life<sup>44</sup>. In other studies, people with hepatitis B described the negative impact that stigma had on employment, getting medical attention, finding emotional support, and socialising and relationships<sup>44,45</sup>.

*Yeah, my, my mental health has been affected, that's for certain. And my emotions and everything has been affected. Yeah, I, I do certain activity once in a while, you know, to kind of, you know, soften the, the effects in my mental health, you know, let's say activity like yoga and meditation, just to calm the calm the tension down. Participant 006\_2023AUHDV*

Participants in this PEEK study described a negative impact on their mental and emotional health, however few had regular activities to maintain their mental health. Some participants described seeing a mental health professional, using mindfulness or meditating techniques, exercising, the importance of their family and friends, and a healthy diet. In terms of maintaining health, participants described complying with treatment and management, exercise, a healthy diet, and socialising with family and friends. Similarly, in another study, people with hepatitis B described mindfulness and meditation complying with treatments, and also living a life as normal as possible, stopping drinking, being organised and informed, and seeking medical attention and clinical trials to maintain physical and mental health<sup>28</sup>

Some participants in this PEEK study described a positive impact on relationships following their diagnosis due to relationships with family being strengthened. However, more commonly participants described a negative impact on relationships from people withdrawing from relationships, the dynamics changing due to anxiety and physical limitations from the condition. They also described that their condition was a burden on their family. In other studies, people with hepatitis B described negative impacts on relationships from social isolation, fear of not being able to form intimate relationships and fear of transmission to family and friends<sup>28,44,45</sup>.

### Key points

- Negative impact on mental health, no activities to manage this
- Negative impact on relationships and quality of life, in part due to reduced socialising

## Characterisation

There were 16 participants with hepatitis D in the study from across Australia. The majority of participants lived in major cities, they lived in areas with higher levels of socioeconomic advantage. Most of the participants identified as Caucasian/white, aged mostly between 25 and 64. Most of the participants had completed some university, and most were employed either full time or part time. They were mostly not carers to family members or spouses.

This is a patient group that had multiple co-morbidities, mostly, depression, anxiety and sleep problems. Less than half of this group currently had other liver conditions.

This is a group whose condition had an impact on health-related quality of life, in particular, physical health often interfered with work and other activities.

This is a patient population that were mostly asymptomatic before diagnosis. For those with symptoms, they were most commonly fatigued.

This is a patient population that experienced no symptoms before being diagnosed. Most participants were diagnosed by their general practitioner.

This is a cohort that were mostly diagnosed with hepatitis D without experiencing symptoms. On average, this group had four diagnostic tests for hepatitis D, they were diagnosed by a general practitioner in a general practice. The cost of diagnosis was not a burden to them and their families. This is a group that did not have enough emotional support or information at the time of diagnosis. This is a cohort that did not have conversations about biomarker/genomic/gene testing. They did not have biomarker or genetic tests but would be interested in having them.

This is a study cohort that had limited knowledge of hepatitis D before they were diagnosed. This patient population described prognosis in terms of medical interventions they need to manage their condition, or were unclear about their prognosis.

This is a patient population that had one treatment option presented to them, and they did not participate in discussions about treatments.

This is a study cohort that took into account their ability to follow treatments, efficacy and side effects when making decisions about their treatment.

Within this patient population participants did not change their decision making over time.

When asked about their personal goals of treatment or care participants most commonly described wanting to maintain their condition or prevent their condition getting worse.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a gastroenterologist, and it usually took less than an hour to travel to medical appointments.

Approximately half of this cohort had private health insurance, half were public patients and most were treated in the public hospital systems This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. Their monthly expenses due to hepatitis D were slightly or not at all a burden.

Participants in this study reduced work hours, or had to take paid leave from work due to their condition. Carers and family did not have to change employment status.

Almost all participants had drug treatments for hepatitis D, usually pegylated interferon alpha. Half of the participants used an allied health service most often a psychologist. More than half made lifestyle changes, usually diet, and approximately a third used complementary therapies, commonly massage therapy or mindfulness and relaxation techniques.

This is a cohort that had conversations about clinical trials, and they would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects as those which can be self-managed and do not interfere with daily life.

This is a study cohort that most commonly could not describe severe side effects because they had not experienced any. Some described them as symptoms such as those that impact every day life, using a specific example or those that are worse than the condition.

This is a patient population which described adhering to their treatment according to the advice of their doctor or as long as prescribed. This is a study cohort that needed to see physical signs and symptoms disappear to feel that treatment is working. If

treatment worked, it would allow them to do everyday activities and return to a normal life.

Participants had good knowledge about their condition and treatments, a good ability to manage the effects of their health condition, good ability to adhere to treatments and communicate with healthcare professionals, and good recognition and management of symptoms.

Participants were given information about disease management, and treatment options from health care professionals, and searched for the same topics independently. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through their treating clinician or the internet.

This is a study cohort that found information about what to expect from the disease, side effects and treatments as being most helpful.

Participants commonly found no information unhelpful, or a lack of new information as unhelpful.

This is a group that preferred online information or talking to someone. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis.

Most participants described receiving an overall negative experience with health professional communication which was dismissive with one-way conversations. Those that experienced good communication with healthcare professionals was because it was holistic, two way and comprehensive.

The participants in this study had moderate communication with healthcare professionals, good navigation of the healthcare system, they rated their care coordination as average, and they participants rated their quality of care as average.

This is a patient population that commonly did not receive any formal support for their condition. Some were supported by other people with hepatitis.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on themselves.

Life was a little distressing for this group, due to having hepatitis D.

This is a study cohort that experienced at least some impact on their mental health and most commonly did no activities to maintain their mental health. Some consulted a mental health professional and others used mindfulness or mediation to maintain their mental health.

Within this patient population, participants described being complying with treatment in order to maintain their general health.

Participants in this study had felt vulnerable especially during or after treatments. To manage vulnerability, they relied on support from family and friends, peer support or took charge of their health.

This cohort most commonly felt there was a negative impact on their relationships, because dynamics of relationships changed due to anxiety of difficult decisions.

Participants felt they were a burden on their family, but that it was only temporary or only during treatment.

Most participants felt there was some cost burden which was from the costs of treatments, and also from having to take time off work.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to come with more open and informed discussions, and for treatments to be easier to administer.

This is a study cohort that would like information to be easier to understand, be more holistic and also to raise community awareness.

Participants in this study would like future communication to allow people more time to meet with their clinician, and to be more transparent and forthcoming.

Participants would like future care and support to include peer support, support groups and online forums.

This patient population was grateful for the healthcare staff, access to specialists, and low cost or free medical treatments through the government.

It was important for this cohort to control fatigue, and liver cirrhosis or fibrosis for quality of life. Participants in this study would consider taking a treatment for less than a year if quality of life is improved with no cure.

Participants' message to decision-makers was that people with hepatitis need timely and equitable access to care and treatment.

This is a patient population that wished they had known to be assertive, to be an advocate and ask their doctor questions. However, many wouldn't change any aspect of their treatment or care.

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