Summary of results

Executive summary

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 of 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 ggastroenterologist, 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.

Section 1

Introduction and methods

Section 1 Introduction and methodology

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)[1]. Coinfection is often acute and will clear within 6 months, however, there is risk of acute liver failure[2]. Superinfection is the most common form of hepatitis, and has a higher risk of cirrhosis and liver cancer[2-4].

Hepatitis D is transmitted through broken skin or blood, transmission can occur from mother to child but it is rare[5]. 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[5,6].

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

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[8]. 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[9]. More males than females have hepatitis D in Australia, at a rate of 2:1[8].

Personal Experience, Expectations and Knowledge (PEEK)

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.

The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Position of this study

A search was conducted in Pubmed (March 6, 2023) to identify studies of hepatitis D, or hepatitis B with patient reported outcomes, or patient experience conducted in the past five years worldwide (Table 1.1). Meta-analysis studies, studies with children, studies in developing countries, and studies of less than five participants were excluded. There were 2 studies identified that included participants with hepatitis D, and 21 studies that included participants with hepatitis B

There were two studies that included participants with hepatitis D, one study was a multi-national study that reviewed emails or social media queries from 65 people with hepatitis D focused on information[16]. The second study included 43 participants with hepatitis D, 82 participants with hepatitis B and collected health-related quality of life by survey[17].

There were 6 studies that collected qualitative data from participants with hepatitis D, there was one study that that reviewed emails or social media queries from 338 participants that was focused on information [18]. There were 28 participants that took part in focus groups that described health literacy[19]. There were four studies that

interviewed between 11 and 23 people with hepatitis B that were focused on stigma[20], decision making[21], quality of life[22] and symptoms[23]

This is the only hepatitis D study of patient reported outcomes, or patient experience conducted in the last 5 years in Australia, and the only study world wide to interview people with hepatitis B about their experiences. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Section 2

Demographics

Section 2 Demographics

Demographics

There were 16 people with hepatitis D that took part in this study, 14 completed the online questionnaire and 12 were interviewed for this study. There were 8 female participants (50.00%), participants were aged from 25 to 74 years of age, most were aged between 25 to 44 years (n=9, 56.25%).

Participants were most commonly from Victoria (n=6, 37.50%), New South Wales (n=5, 31.25%), and Queensland (n=3, 18.75%). Most participants were from major cities (n=13, 81.25%), and they mostly lived in areas with higher socioeconomic advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 2 participants (12.50%) from an area with a mid to low SEIFA score of 1 to 6 (less advantage), and 14 participants (87.50%) from an area of higher SEIFA scores of 7 to 10 (more advantaged).

There were 9 participants (56.25%) that had completed university to at least an associate degree. There were 9 participants who were in paid employment. There were 4 participants (28.57%) were carers to family members or spouses, most commonly carers to children, parents (n=2, 14.29%).

Other health conditions

The majority of participants had at least one other condition that they had to manage (n=12, 85.71%), the maximum number reported was 13 other conditions, with a median of 3.50 other conditions (IQR = 5.00) (Table 2.3, Figure 2.2). The most commonly reported health condition was depression (self or doctor diagnosed) (n=7, 50.00%), followed by anxiety (self or doctor diagnosed) (n=7, 50.00%), sleep problems or insomnia (n=6, 42.86%), and hypertension (n=5, 35.71%).

Baseline health

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health often interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems sometimes interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being** scale measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning** scale measures limitations on social activities due to physical or emotional problems. On average, social activities were moderately limited for participants in this study.

The **SF36 Pain** scale measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

The **SF36 General health** scale measures perception of health. On average, participants reported average health.

The **SF36 Health change** scale measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 8 participants (57.14%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and an average of 2.36 symptoms (SD=3.05).

Symptoms before diagnosis

The most common symptoms before diagnosis were being tired, fatigued, or generally weak (n=6, 42.86%), abdominal pain (n=4, 28.57%), muscle or joint aches and pains (n=4, 28.57%), and loss of appetite (n=3, 21.43%).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life for fatigue was 3.00 (IQR = 2.25), in the "Life was a little distressing" range.

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Most commonly participants had no symptoms (50.00%). Others strongly recalled their symptoms or how they came to be diagnosed (33.33%) or had an unclear recollection of their symptoms or how they came to be diagnosed (16.67%).

The most common symptoms leading to diagnosis was fatigue (25.00%), and nausea and vomiting (16.67%). Other symptoms included appetite loss (8.33%), brain fog (8.33%), joint aches (8.33%), muscle aches (8.33%), reflux or digestive problems (8.33%), sleep problems (8.33%), and dark urine (8.33%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were having no symptoms or not noticing any symptoms before diagnosis (50.00%) and having symptoms and not seeking medical attention initially (33.33%). Other themes included having symptoms and seeking medical attention relatively soon (8.33%) and being diagnosed as a child (8.33%).

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common descriptions were being diagnosed by their general practitioner during a check-up related to symptoms (33.33%), being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (25.00%), and a linear diagnosis after being referred to a specialist from their general practitioner (16.67 %). Other themes included being diagnosed in an emergency department (8.33%), being diagnosed from physical as part of immigration tests (8.33%), and not being able to remember (8.33%).

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of hepatitis D and the approximate date of diagnosis with hepatitis D . Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 6 participants (8 participants had no symptoms before diagnosis), there were 4 participants (66.67%) that were diagnosed within a year of noticing symptoms, 2 participants (33.33%) diagnosed more than a year from noticing symptoms.

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

Participants were were most commonly diagnosed immediately at the consultation (n = 2, 14.29%). There were 2 participants (14.29%) that were diagnosed less than one week after diagnostic tests, 3 participants (21.43%) diagnosed between 1 and 2 weeks,2 participants (14.29%) diagnosed between 2 and 3 weeks,1 participants (7.14%) diagnosed between 3 and 4 weeks, and 2 participants (14.29%) diagnosed more than four weeks after diagnostic testing.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with hepatitis D. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 1 and 9 diagnostic tests (median=4.00 , IQR=3.00). The most common tests were blood tests for Hepatitis B infection (n=13, 92.86%), blood tests for Hepatitis D infection (n=13, 92.86%), blood tests for liver function (n=6, 42.86%), and blood tests for Hepatitis C infection (n=5, 35.71%).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a general practitioner (GP) (n=8, 57.14%), and there were 6 participants (42.86%) given the diagnosis by a specialist doctor.

Participants were most commonly given their diagnosis in the general practice (GP) (n=8, 57.14%), this was followed by the hospital (n=3, 21.43%), and the specialist clinic (n=3, 21.43%).

Hepatitis Vaccinations

Most participants had a Hepatitis A vaccination (n=10, 71.43%), and a Hepatitis B vaccination (n=9, 64.29%).

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. Most commonly participants knew nothing or very little about the condition at diagnosis (75.00%) Other participants described knowing about the condition including causes and risk factors (25.00%).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 2 participants (14.29%) who had enough support, 2 participants (14.29%) that had some support but it wasn't enough, and 10 participants (71.43%) had no support.

Information at diagnosis

Participants were asked in the online questionnaire how much information they or their family received at diagnosis.

There were 3 participants (21.43%) who had enough information, 5 participants (35.71%) that had some information but it wasn't enough, and 6 participants (42.86%) had no information.

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 7 participants (50.00%) who had no out of pocket expenses, and 5 participants (35.71%) who did not know or could not recall. There were 2 participants (14.29%) that spent between $50 and $150.

Burden of diagnostic costs

In the follow-up question about the burden of costs at diagnosis, for 30 participants who had out of pocket expenses.

For 5 participants (35.71%) the cost was slightly or not at all significant, and for 2 participants (14.29%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=8, 57.14%). There was 1 participant (7.14%) who brought up the topic with their doctor, and 5 participants (35.71%) whose doctor brought up the topic with them.

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

Offered liver checks every 6 months

Participants were asked in the online questionnaire if they were offered liver checks at least every 6 months. The majority of participants were offered liver checks every 6 months (n=9, 64.29%)

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were that they had specific medical interventions they need to manage their condition (25.00%), and that there was uncertainty around prognosis (25.00%). Other themes included that their prognosis was positive, that their condition is manageable (16.67%), that there was no evidence of disease or that they are in remission (16.67%),that they were monitoring their condition until there is an exacerbation or progression (16.67%), that it being currently controlled (8.33%), and in relation to the risk of liver cancer (8.33%).

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with one treatment option (50.00%). Other participants had no discussions about treatment (25.00%), multiple options (16.67%), or they could not remember (8.33%).

Discussions about treatment (Participation in discussions)

In relation to participant in discussions about treatments, some participants were presented with no treatment options describing that no therapies were available (8.33%), and having no discussions about treatments without giving a reason (8.33%), and no discussions about treatments because of competing health issues (8.33%).

For those with a single treatment option, most commonly they did not participate in the decision-making process (16.67%). Some participated in the decision-making process (8.33%), and others gave no reason (25.00 %). For those presented with multiple treatment options, most commonly they did no give a reason (16.67%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were ability to follow treatments (41.67%), efficacy (41.67%), and side effects (41.67 %). Other themes included cost (25.00%), ability to work (16.67%), impact on their family or dependents (8.33%), and own research (8.33%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. Less than half described not changing the way they make decisions (41.67%), and approximately a third had changed the way they make decisions (33.33%).

Where participants had changed the way they make decisions, the most common reasons were that they were more aware of their health, responsibilities and/or limitations (16.67%), more accepting of their condition (8.33 %), and does not mention any reason (8.33%).

Where participants had changed the way they make decisions, most commonly they did not give a reason (25.00%), followed by always been informed/assertive (8.33%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common responses were to maintain their condition or prevent worsening of their condition (41.67%), and have quality of life or return to normality (25.00%). Other themes included minimise or avoid side effects (16.67%), make healthy lifestyle changes (16.67%), have improvements in mental or emotional health (8.33%), comply with treatment (8.33%), and be there for family (8.33%).

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

The most common provider of treatment and care were gastroenterologists (n=9,64.29 %), followed by general practitioners (n=5, 35.71%).

Time to travel to main provider of treatment

Participants were asked in the online questionnaire how long they had to travel for to get to their appointments with their main treatment provider.

There were 6 participants (42.86%) that travelled for less than 30 minutes, 4 participants (28.57%) that travelled between 30 and 60 minutes, 2 participants (14.28%) that travelled for more than 60 minutes.

Ease of getting medical appointments

Participants were asked in the online questionnaire how easy it was to get appointments with their main treatment provider.

There were 3 participants (21.43%) found it not very easy, 2 participants (14.29%) that found it somewhat easy, 6 participants (42.86%) that found it quite easy, and 3 participants (21.43%) that found it very easy to get an appointment with their main treatment provider.

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

Almost all participants had access to a gasteroenterologist (n=8, 57.14%), and more than half had access to a Hepatologist (n=8, 57.14%). There were 12 participants (85.71%) that had a general practitioner (GP) and 5 participants (35.71%) that had a hepatology nurse.

There were 6 participants (42.86%) that had access to a pharmacist, and 3 participants (21.43%) treated by a dietitian/nutritionist.

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

There were 8 participants (57.14%) that indicated that they had been treated with respect throughout their experience, and 5 participants (35.71%) that were treated with respect with the exception of one or two occasions. There was one participant (7.14%) that felt they had not been treated respectfully at all.

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient.

The majority of participants had private health insurance (n=7, 53.85%). The majority of participants were not asked if they wanted to be treated as a public or private patient (n=8, 61.54%), however, they were asked if they had private health insurance (n=10, 76.92%).

Throughout their treatment, there was 1 participant (7.69%) that was treated as a private patient, 7 particpants (53.85%) were mostly treated as a public patient, and there were 2 particpants (15.38%) that were equally treated as a private and public patient.

Throughout their treatment, there were 2 participants (15.38%) that were treated mostly in the private hospital system, 10 particpants (76.92%) were mostly treated in the public system, and there was 1 particpant (7.69%) that was equally treated in the private and public systems.

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire. The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 9, 69.23%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=9, 69.23%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 9 participants (69.23%) that never or rarely had trouble paying for essentials, and 4 participants (30.77%) that sometimes found it difficult, and 0 participants (0.00%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were 3 participants (23.08%) that paid for additional carers due to their condition.

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed below (Table 5.8, Figure 5.9).

The most common amount was between $1 and $150 (N=5, 38.46%). There were 2 participants (15.38%) that did not spend anything, and the same number that spent more than $100 per month.

Burden of cost

As a follow up question, for participants that had monthly expenses due to their condition, participants were asked if the amount spent was a burden.

The amount spent was an extremely significant or moderately significant burden for 4 participants (30.77%), somewhat significant for 1 participants (7.69%), and slightly or not at all significant for 8 participants (61.54%).

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment.

Work status for 3 participants (23.08%) had not changed since diagnosis, and 0 participants (0.00%) were retired or did not have a job. There was 1 participant (7.69%) had to quit their job, 5 participants (38.46%) reduced the number of hours they worked, and 2 participants (15.38%) that accessed their superannuation early. There were 2

participants (15.38%) that took leave from work without pay, and 3 participants (23.08%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment.

There were 3 participants (23.08%), without a main partner or carer. Most commonly, participants had partners or carers that did not change their work status due to their condition (n=6, 46.15%). There was 1 participant (7.69%) whose partner reduced the numbers of hours they worked, and 1 partner (7.69%) that quit their job. The partners of no partners of participants (0.00%) that took leave without pay, and there was 1 partner (7.69%) that took leave with pay.

Reduced income due to condition

Almost a third of the participants (n=4, 30.77%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition.

There were 4 participants (30.77%) with a reduced monthly income, and 9 participants (69.23%) with no reduced income.

Summary of treatments and management

Participants noted in the online questionnaire the different treatments, allied health services, complementary therapies, and lifestyle changes they had since diagnosis with their condition.

The majority of participants had drug treatments (n=13, 92.86%), and 7 participants (50.00%) that used allied health. Participants used complementary therapy (n=5, 35.71%), made lifestyle changes (n=8, 57.14%). There was 1 participant (7.14%) that had no treatment, 1 participant (7.14%) that had a liver transplant.

Summary of drug treatments

Participants completed a series of questions about drug therapies, including, quality of life, effectiveness of treatment, and side effects. .

The majority of participants had drug treatments (n=13, 92.86%). The most common types of drug treatments were Pegylated interferon alpha (Pegasys, Peg-Intron), (n=11, 78.57%), Entecavir (Baraclude) n=4,28.57%) and, Ribavirin (Ibavyr) (n=4,28.57%).

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Values are calculated where there was adequate data available (five or more participants).

On average, quality of life from Pegylated interferon alpha (Pegasys, Peg-Intron) was in the 'life was distressing' range (median=2.00, IQR=1.00), and was found to be ineffective (median=1.00 , IQR=3.00).

Allied health

The most common allied health service used was psychology (n=4, 28.57%), followed by dietary (n=3, 21.43%), and social work (n=2, 14.29%). There were 1 participant (7.14%) that saw a physiotherapist , 1 participant (7.14%) that saw a podiatrist. No participants had speech therapy or occupational therapy.

Lifestyle changes

Participants were asked about any lifestyle changes they had made since diagnosis, the quality of life from these changes, and how effective they found them.

Most participants used at made at least one lifestyle change (n=8, 57.14%).

The most common lifestyle change used was diet changes (n=7, 50.00%), followed by reducing or quitting alcohol (n=6, 42.86%), and exercise (n=4, 28.57%).

On average, quality of life from diet changes was in the 'life was average' range (median=4.00, IQR=2.00), and was found to be moderately (median=3.00, IQR=1.50).

On average, quality of life from reducing or quitting alcohol was in the 'life was average' range (median=4.00, IQR=1.50), and was found to be very effective (median=5.00, IQR=0.75).

Complementary therapies

Participants were asked about any complementary therapies they used to manage their condition, the quality of life from these changes, and how effective they found them.

Approximately a third of participants used at least one complementary therapy (n=5, 35.71%)

The most common complementary therapy used was , massage therapy (n=4, 28.57%), followed by mindfulness or relaxation (n=4, 28.57%), and supplements (n=3, 21.43%).

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion.

There was a total of 8 participants (57.14%) that had discussions about clinical trials, 3 participants (21.43%) had brought up the topic with their doctor, and the doctor of 5 participants (35.71%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=6, 42.86%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part.

There was 1 participant (7.14%) that had taken part in a clinical trial, 10 participants (71.43%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (21.43%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common descriptions of mild side effects were those that do not interfere with life (50.00%), and they described

mild side effects using a specific example (50.00%). Other themes included those that can be managed with self-medication or self-management (8.33%), and those that resolve in short time (8.33%).

When a specific side effect was described, the most common responses were headaches (16.67%), and skin itch or rash (16.67%). Other themes included aches and pain (8.33%), emotional or mental impact (8.33%), gastrointestinal distress (8.33%), lightheadedness or being dizzy (8.33%), nausea or loss of appetite (8.33%), heavy periods and low blood iron (8.33%), and low immunity (8.33%).

Description of severe side effects

In the structured interview, participants were asked how they would describe the term 'severe side effects'. The most common description of severe side effects were those that impact everyday life or ability to conduct activities of daily living (16.67%), described using a specific example (16.67%), and that the treatment is worse than condition (16.67%). Other themes included those that are life threatening or result in hospitalisation (8.33%), those that cause long-term damage to their body (8.33%), those that requires medical intervention (8.33%), and those that impact their everyday life by being bed ridden (8.33%).

When a specific side effect was described, the examples were aches and pain (8.33%), and emotional and mental impact (8.33%), fatigue and lethargy (8.33%), and allergic reaction (8.33%).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common responses were adhering to treatment according to the advice of their specialist or as long as prescribed (58.33%), needing to see test results/no evidence or reduction of disease (33.33%), and adhering to treatment as long as side effects are tolerable (16.67%).

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were needing to see physical signs and symptoms disappear/reduce side effects (25.00%), needing to see evidence of stable disease or no disease progression (16.67%), and needing to see a specific symptom reduction (8.33%).

When a specific side effect or symptom was described, they were aches and pain (16.67%), cognitive difficulties (8.33%), fatigue and lethargy (8.33 %), and night sweats (8.33%).

What it would mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were that it would allow them to do everyday activities/return to normal life (33.33%), and have a positive impact on their mental health (25.00%). Other themes included lead to a reduction in symptoms and side effects (8.33%), less medical interventions, doctor visits, or hospitalisation (8.33%), and a longer life (8.33%).

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were their treating clinician (58.33%), the internet (41.67%), and health charities (25.00 %). Other sources included other patient's experience (Including support groups) (16.67%), books, pamphlets and newsletters (8.33%), and Facebook or social media (8.33%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be most helpful. The most common responses were hearing what to expect (e.g. from disease, side effects, treatment) (58.33%), other people's experiences (Peer-to-peer)(25.00%), and talking to a doctor or specialist or healthcare team (25.00 %). Other helpful information included information from health charities (8.33%), information about lifestyle changes (8.33%), and information about transmission (8.33%).

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common response was that there was no information that wasnot helpful (50.00%). Information that was not helpful included and a lack of new information (16.67%), information from their GP or specialist (8.33%), sources that are not credible (not evidence-based) (8.33%), information that is not comprehensive (8.33%), and information that is accompanied with stigma and discrimination (8.33%).

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were talking to someone (33.33%), and talking to someone plus online information (33.33%). Other preferences included online information (16.67%), all forms (16.67%), and written information (8.33%).

The main reasons for a preference for online information were that it is personalised and relevant (41.67%), being able to\have time to ask questions (Talking to someone) (25.00%), and No strong reason for preference\Personal preference (25.00 %). Other themes included Accessibility (Internet) (16.67%), Being able to digest information at their own pace (Internet) (8.33%),written information because you can refer back to/highlight important information (8.33%), and online information because it is reliable information and you are able to decide if trustworthy (8.33%).

The main reasons for a preference for online information was because of the ease of accessibility (16.67%), because it is personalised and relevant (16.67%), because it is reliable information and you are able to decide if trustworthy (8.33%), and because they are able to digest information at their own pace information at their own pace (8.33%).
The main reasons for a preference for talking to some one because they are able to ask questions (25.00%), and because it is personalised and relevant (25.00%).
The main reasons for a preference for written information because you can refer back to/highlight important information (8.33%)

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (33.33%), and continuously (25.00%). Other times included after the shock of diagnosis (16.67%), when something needs treatment/attention/change in management (16.67%), and at a specific time in the day (8.33%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. Half of the participants described communication as overall negative (50.00%), a quarter described communication as overall negative (25.00%), 16.67% had overall positive communication with the exception of one or two occasions, and 8.33% had a mix of both positive and negative communication.

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had negative communication, described the reason for this was because of dismissive one way conversations (25.00%), communication was limited in time (25.00%), communication was limited in understanding (8.33%), healthcare professionals used difficult medical terms (8.33%), participants felt disrespected vulnerable (8.33%), and that information that was withheld or not freely given (8.33%).

Participants that had positive communication, described the reason for this was because of holistic two way, supportive and comprehensive conversation) (25.00%).

Partners in health

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had a good ability to manage the effects of their health condition.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average participants in this study had a good ability to adhere to treatments and communicate with healthcare professionals.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average participants in this study had good recognition and management of symptoms.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average participants in this study had good overall knowledge, coping and confidence for managing their own health.

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n=10, 76.92%), and 1 participant (7.69%) responded that they took medicines as prescribed most of the time. There were 2 participants (15.38%) that sometimes took medicines as prescribed.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=10, 76.92%), disease management (n=7, 53.85%), interpret test results (n=5, 38.46%) and, psychological/ social support (n=4, 30.77%) were most frequently given to participants by healthcare professionals, and, information about dietary (n=2, 15.38%), hereditary considerations (n=2, 15.38%) and, complementary therapies (n=1, 7.69%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were treatment options (n=7, 53.85%), disease management (n=7, 53.85%), disease cause (n=5, 38.46%) and, complementary therapies (n=5, 38.46%) were most frequently given to participants by healthcare professionals, and, information about physical activity (n=4, 30.77%), hereditary considerations (n=2, 15.38%) and, clinical trials (n=1, 7.69%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=10, 76.92%) and Pphysical activity (n=10, 76.92%).

The topics that participants did not search for independently after receiving information from healthcare professionals were treatment options (n=4, 30.77%) and disease cause (n=3, 23.08%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=6, 46.15%) and disease management (n=6, 46.15%).

The topics that participants searched for independently after not receiving information from healthcare professionals were disease cause (n=5, 38.46%) and complementary therapies (n=4, 30.77%).

Most accessed information

Participants were asked to rank which information source that they accessed most often. Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Government. Information from Medical journals and from Pharmaceutical companies were least accessed.

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

The **Care coordination: communication** scale measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. The average score indicates that participants had moderate communication with healthcare professionals.

The **Care coordination: navigation** scale navigation of the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. The average score indicates that participants had good navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. The average score indicates that participants had moderate communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. The average score indicates that participants scored rated their care coordination as average.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. The average score indicates that participants rated their quality of care as average.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common response was that they did not receive any formal support (41.67%). Others described getting support from peer support or other patients (16.67%), charities (8.33%), community or religious groups (8.33%), family and friends (8.33%), hospital or clinical setting (8.33%), and financial support including financial counselling (8.33%).

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Half of the participants descriptions suggested that there was an overall negative impact on quality of life (50.00%). Others described an overall a minimal impact on quality of life (16.67%), overall no impact on quality of life (16.67 %), and a mix of positive and negative impact on quality of life (8.33%).

The most common themes in relation to a negative impact on quality of life were emotional strain on self (41.67%), emotional strain (including family/change in relationship dynamics) (33.33%), and reduced social interaction (25.00 %). Other themes included managing side effects and symptoms (8.33%), and from stigma and discrimination (8.33%). The most common theme in relation to a positive impact on quality of life was that it brings people together/highlights supportive relationships (8.33%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (83.33%), and overall, there was no impact on mental health(8.33%).

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was that they did not have any activities to maintain mental health (41.67%). Others described maintaining their mental health by consulting a mental health professional (16.67%), mindfulness and/or meditation (16.67 %), the importance of physical exercise (8.33%), the importance of family and friends in maintaining their mental health (8.33%), and importance of a healthy diet (8.33%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health. The most common activities for general health were complying with treatment/management (33.33%), and doing physical exercise/physically active (16.67%), Other themes included maintaining a healthy lifestyle (16.67%), maintaining a healthy diet (8.33%), socialising with friends and/or family (8.33%), and getting help with translating health information (8.33%).

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable during/after treatments (25.00%), all the time (16.67%), when having sensitive discussion (diagnosis, treatment decision) (16.67 %), and vulnerable because of feelings of stigma (16.67%). Other themes included feeling vulnerable waiting for results (8.33%), and because of interactions with the medical team (8.33%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common ways to manage vulnerability were getting support from family and friends (8.33%). peer support (8.33 %) and taking charge of own health (8.33%).

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (41.67%), overall. Others described that there was no impact on relationships (16.67%), and overall, there was a positive impact on relationships (16.67 %).

The most common theme in relation to having a positive impact on relationships was from family relationships being strengthened (16.67%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (16.67%). This was followed by from the dynamics of relationships changing due to anxiety, exacerbations and/or physical limitations of condition (8.33 %), and from assigning blame for infection (8.33%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (66.67%), overall, there was not a burden on their family(16.67%), and overall, there was not a burden on their family now but they anticipate this will change in the future (8.33 %).

The main reason that participant described their condition being a burden was that the burden on family was temporary or only during treatment (41.67%). Others described that their condition was a burden in general (25.00%) the mental/emotional strain placed on their family (16.67 %), and the extra financial assistance needed (8.33%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. Most commonly participants described that there was at least some cost burden (58.33%), and a third described that overall, there was no cost burden (33.33%).

Where participants described no cost burden associated with their condition, it was most commonly because nearly everything was paid for through the public health system (16.67%), nearly everything was paid for through the private health system (8.33%), and being able to afford all costs (8.33 %).

Where participants described a cost burden associated with their condition, it was most commonly in relation to the cost of treatments (including repeat scripts) (25.00%), needing to take time off work (16.67%), the cost of parking and travel to attend appointments (including accommodation) (8.33 %), and allied health care (8.33%).

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is life was great. The average score was in the Life was a little distressing range (median=3.00, IQR=3.50).

Fear of progression

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will include having choice including accessibility, transparency and discussions in relation to treatment options (33.33%), and treatments will be easier to administer or they will be able to administer at home and/or less invasive (25.00%). Other themes included that treatment will be curative (16.67%), treatments will be more affordable (16.67%), they will have fewer or less intense side effects/more discussion about side effects (16.67%), involve a more holistic approach (8.33%), allow for a normal life/quality of life (8.33%), and that while treatments are important prevention, awareness and education are also important (8.33%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be easier to understand (16.67%) be more holistic including information about emotional health (16.67%). And will help to inform the community and decision-makers about their condition (raise awareness) (16.67%). Other themes included that information will be in a variety of formats (8.33%), be more accessible/easy to find (8.33%), include the ability to talk to/access to a health professional (8.33%), provide more details about disease trajectory and what to expect (8.33%), provide more details about where to find support (including peer support/support groups) (8.33%), and provide more details to support carers (8.33%), information will be available in languages other than English (8.33%), and that information will provide more details about transmission (8.33%).

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will allow people more time to meet with their clinician (25.00%), and be more transparent and forthcoming (25.00%). Other themes included that communication will be more empathetic (16.67%), include listening to the patient (8.33%), include developing a care plan with follow-up (8.33%), will be more understandable (8.33%), and will raise awareness of the condition (8.33%).

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include being able to connect with other patients through peer support (support groups, online forums) (25.00%), this was followed by care and support will include more access to support services (16.67%), it will include specialist clinics or services where they can talk to professionals (in person, phone, online) (16.67 %), it will be more holistic (including emotional health) (16.67%), and will include practical support (home care, transport, financial) (16.67%). Other themes included that care and support will include a multidisciplinary and coordinated approach (8.33%), will include health professionals with a better knowledge of the condition (8.33%), and will include support in non-English languages (8.33%).

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for healthcare staff (including access to specialists) (33.33%), low cost or free medical treatments through the government (33.33%), and low cost or free medical care through the government (16.67 %). Other things that participants were grateful for were access to private healthcare and private insurance (8.33%), the entire health system (8.33%), timely access to diagnostics (8.33%). Participants also noted the need for quicker access to treatments (8.33%), the need for more access to

experts in condition to answer questions and for healthcare professionals to be aware of the condition (8.33%), and not being grateful for anything (8.33%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were feeling tired, fatigued, or generally weak, liver cirrhosis or fibrosis and, nausea and/or vomiting. The least important were swollen abdomen, loss of appetite and, muscle or joint aches and pains.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure. Most commonly participants would use a treatment for more than ten years (n = 4, 30.77%), or less than a year n = 4, 30.77%), for a good quality of life even if it didn’t offer a cure.

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There were 2 participants (15.38%) that thought that medicine delivered by IV was most effective, 6 participants (46.15%) thought that pill form was most effective, and 4 participants (30.77%) that thought they were equally effective.

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common message to the health minister was the need for timely and equitable access to support, care and treatment (50.00%). Other messages were that treatments need to be affordable (16.67%), there is a need to invest in research (including to find new treatments) (16.67 %), to help raise community awareness (16.67%), to have a holistic approach to the condition (including emotional support) (16.67%), and that they were grateful for the healthcare system and the treatment that they received (8.33%).

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to be assertive, an advocate, informed, and to ask questions (50.00%), and that they had understood the cause and risk factors of the condition (16.67%). Other themes included to be open to complementary approaches (8.33%), to look after emotional wellbeing (8.33%), that there was more community awareness of their condition (8.33%), and that they had understood the extent of the transmission risk they posed to others (8.33%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common theme was that they would not change any aspect of their care or treatment (41.67%). Others would have stopped or changed treatment sooner (8.33%), would have liked to have had access to a specialist in their condition sooner (8.33 %), they would have liked to have access to care closer to home (8.33%), they would have liked to have access to doctors that speak their language (8.33%), and they would have liked to have had more monitoring of their condition and earlier access to treatment (8.33%).