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Research

'I'm over the moon!': patient-perceived outcomes of hepatitis C treatment

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Abstract. Understanding patient-perceived outcomes is crucial for assessing the effectiveness and acceptability of hepatitis C virus (HCV) treatment. This study aimed to explore patient-perceived outcomes of receiving direct-acting antivirals (DAAs). This study was a part of a mixed-methods case study of the Prince Charles Hospital program for improving access to HCV treatment in community settings. Data were collected using semi-structured interviews with nine patients who were in different stages of their treatment for HCV. The participants were recruited using purposive sampling. All interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis. Patients emphasised 'having more energy' when reporting improvements in their physical health following treatment. They also reported a newly developed sense of freedom and hope. Improved physical and mental health empowered them to start a healthy lifestyle and to practise self-protection from the risk of re-infection. Patients highlighted their desire to help other patients to receive treatment, which was connected to their experience of the services that they received and their perceived health outcomes. Patients expect and experience various outcomes that are related to the physical, psychological and social aspects of living with, and being cured of HCV. Emphasis on the short-term outcomes of receiving HCV treatment may improve HCV treatment uptake and adherence rates.

Additional keywords: DAAs, patient outcome assessment, primary health care, quality of life.

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Introduction

The World Health Organization (WHO) has set a target to eliminate the hepatitis C virus (HCV) as a public health threat by 2030 (WHO 2018). To realise this, 80% of patients with HCV need to receive treatment (WHO 2018). In Australia, all patients with HCV are eligible to receive subsidised (nearly free) direct-acting antiviral (DAA) drugs (Hepatitis C Virus Infection Consensus Statement Working Group 2018). Although the availability of DAA therapies removed barriers related to interferon-based treatment, there remain other barriers that prevent patients from accessing HCV treatment (Pourmarzi *et al.* 2020). Patients' socioeconomic characteristics, internalised stigma, perception of not being sick, and lack of knowledge; in addition to health care providers' lack of knowledge, their perception of HCV, and patients with HCV; and unavailability of support for patients and existence of stigma in the health system impede patients' engagement with HCV treatment (Pourmarzi *et al.* 2020). Considering these barriers, the availability of DAA is only one factor influencing treatment uptake (Treloar *et al.* 2014; Pourmarzi *et al.* 2019*a*, 2019*b*, 2020). In this context, narrowly defining HCV as a medical condition, with the potential for liver and extrahepatic disease at some point in the future, may not encourage patients to initiate HCV treatment (Madden *et al.* 2018*a*; Richmond *et al.* 2018; Wallace *et al.* 2018).

An understanding of patients' expected outcomes of HCV treatment may be helpful for communicating effectively and engaging with people who require testing and treatment, including priority populations, for HCV elimination (e.g. people who inject drugs) (Madden *et al.* 2018*a*, 2018*b*; Stewart 2001). This may also provide a more complete picture of treatment effect and may encourage the involvement of healthcare providers and policymakers in HCV treatment (Wu *et al.* 2010; Goutzamanis *et al.* 2019).

Patient-reported outcomes have been defined as reports that come from patients about their health status without interpretation by the clinician or anyone else (Deshpande *et al.* 2011). Studies on patient-reported outcomes have usually used structured health status questionnaires, such as the SF-36 or CLDQ-HCV, to measure different aspects of medically oriented treatment outcomes (Younossi *et al.* 2016; Younossi *et al.* 2019). A systematic review on patient-reported outcomes of receiving HCV treatment showed that patients' quality of life after receiving interferon-based treatment worsen compared with before starting the treatment, whereas it was improved after receiving DAAs-based treatment as early as 2 week after initiating treatment (Younossi and Henry 2015). Although using structured health status questionnaires helped us to have some insights into patients' experience with receiving treatment, there are some limitations to these types of measures. Many patients are asymptomatic and even for some patients with HCV disease symptoms, the psychological and social aspects of having HCV may be more significant than these symptoms (Harris 2017; Madden *et al.* 2018*a*; Goutzamanis *et al.* 2019). Further, using structured questionnaires can limit patients' ability to report their experienced outcomes (Deshpande *et al.* 2011). A qualitative approach, which provides space for patients to express their own feelings and experiences, can be helpful for developing a greater understanding of patient-perceived outcomes of HCV treatment. This study aimed to explore patient-perceived outcomes of receiving DAAs therapies.

Methods

This study is a part of a mixed-methods case study of the Cure-It program. The program was a real-world practice implemented in March 2016 in The Prince Charles Hospital, Brisbane, Queensland, Australia, and aimed at improving access to HCV treatment through providing training and ongoing support for primary care providers in community settings. The program is further described elsewhere (Pourmarzi *et al.* 2019*c*). As part of that case study, we explored the patients' experienced outcomes as a result of receiving HCV treatment through the program.

Data for this part of the case study were collected using semi-structured interviews with nine patients between July and December 2018. Participants were recruited using two types of purposive sampling, including criterion sampling and snowball sampling (Palinkas *et al.* 2015). In this study, based on criterion sampling, the researcher targeted patients who experienced the Cure-It program. Patients from all stages of treatment were considered for sampling. Based on snowball sampling, the researcher asked some HCV care providers, who had participated in the case study, to introduce the study to their patients who may have wished to participate. The HCV care providers delivered the study flyer to their patients or introduced the researcher to key persons in their organisation to help the researcher to recruit patients. In the recruitment process, whether the participants were able to communicate their experiences and opinions in an expressive and reflective manner, was also considered. The two main questions that we used to explore patients' experience with the treatment included: 'What is/has been your experience with HCV treatment?' and 'What encouraged you to initiate and continue the treatment?'. The follow-up questions were asked based on participants' responses. Data analysis performed during data collection and sampling continued until saturation was achieved.

The principal researcher (D. Pourmarzi) who conducted all the interviews and data analysis, was not involved in the Cure-It program nor in providing care for patients. All interviews were audio-recorded and transcribed verbatim. The interview transcripts were analysed using inductive thematic analysis (Braun and Clarke 2006). Data were managed using NVivo version 10 (QSR International Pty Ltd, Melbourne, Vic., Australia).

Ethics considerations

The study protocol was approved by the Prince Charles Hospital Human Research Ethics Committee (approval number HREC/17/QPCH/453). Written or verbal consent was obtained from all participants before starting the interviews. To compensate participants for their time, all participants received a 30 AUD grocery voucher. To prevent unintended identification of patients, participants' names and demographic data were not collected and the audio-recorded files, interview guides and interview transcripts from each participant were assigned a unique code. In this report, 'PG', 'PD' and 'PH' refer to patients from general practices, drug and alcohol services and the hospital, respectively.

Results

Characteristics of interview participants

Between July 2018 and December 2018, nine patients were interviewed. Three interviews were conducted by telephone, whereas the other interviews were conducted face-to-face. The interview duration varied from 21 to 48 min.

The participants included two patients who had received treatment from the hospital, six patients who had received or were receiving treatment from drug and alcohol services, and one patient who had received treatment from a general practice. One of the patients was now working as a peer harm-reduction worker. At the time of the interview, six patients were cured and three patients were still undergoing treatment. Of those under treatment, one patient had a history of re-infection and discontinuation after receiving initial DAA treatment. Five patients were male and four were female. We did not ask about patients' injecting drug use, but seven patients during the interview reported that they contracted HCV through injecting drug use. Further data on patient characteristics were not collected.

Patient-perceived outcomes

Patients reported a range of positive outcomes as a result of initiating HCV treatment or being cured of HCV. Improvements of physical and mental health, looking after themselves, self-preservation and a desire to help other patients were reported by patients as a result of their access to HCV treatment.

Improved physical health

Receiving HCV treatment resulted in improvements in patients' physical health – referred to as having more energy when compared with their pre-treatment status. Patients reported that they did not think that symptoms such as fatigue and lethargy they experienced were related to HCV, until

receiving HCV treatment. They had considered the experienced symptoms to be 'normal', because they were living with them for a long time or attributed the symptoms to their drug or alcohol use.

> …. I feel brilliant. I feel positive and healthy, … I feel a change, yeah. Really do feel the change. Where I used to be fatigued and lethargic, and you know? Not today. I bounce around everywhere [PD5].

> I was always tired all the time. I was depressed. … I would have never been able to last a whole day without having a sleep. I never had any energy. My back was sore, my lower back. Just lethargic all the time. … I just thought that was normal. Because I was still using drugs, I thought I was just coming down off the drugs and stuff, but until I started the treatment, it wasn't normal at all. It was hep C [PD1].

Improved mental health

Patients also reported improved mental health, referring to their emergent sense of freedom and hope as a result of receiving treatment for HCV and of being cured. They described initiating HCV treatment and getting rid of the HCV as 'big freedom'. The freedom was related to the removal of internalised stigma and concerns of experiencing stigma and discrimination at the health system and from society.

> To live with the disease that I contracted using drugs. … You have to reveal it everywhere you go. How shame[ful] is that? … So, lot of shame, guilt, you know? … I have a disease, addiction that's in my brain, but I don't have a disease in my body today. It's cured. That's a big free [PD5].

Curing HCV for some of the patients was a 'big relief' as they no longer needed to be concerned about infecting other people. This was especially highlighted among patients who had young children.

> I've got two little girls,… You've got to hide, move your toothbrush. You've got to think of everything. … You always have to tell dentists. …. So it's a big relief when it'll be gone [PD6].

Initiating HCV treatment and being cured of HCV helped patients to develop a sense of hope. They saw HCV as a disease that made their whole life unmanageable, and curing it helped them to manage their life and have expectations for a better life ahead.

> Because your life has been unmanageable all your life because of this disease, you know? You clear it, your life becomes manageable, you know? You are back in control. I had the last, say, 25 years with it. I just turned 41, so the next 40 will be good you know? [PD5].

> I'm a bit more forthcoming with things now. … my life is opening up a little bit better now. I don't have that weight on my back anymore [PH1].

For many patients who were aware of HCV consequences, curing HCV meant a longer life expectancy. This was especially important for parents, as they could be alive to support their children.

> I'm over the moon. To me, it means that I'm going to be here longer for my kids, … I'm yeah, really happy actually. Really happy [PG1].

Looking after themselves

Experiencing improvement in physical and mental health and developing a sense of hope empowered patients to start a healthy lifestyle. Patients reported that they were looking after themselves better after initiating the treatment or being clear of the virus. Having a healthy diet, doing physical activity and not using drugs were reported by participants as a way to keep themselves healthy.

> It's time for me to try for myself, mate. I'm eating healthy and getting sleep and just because of staying off the grass now. Since I was eleven, I've smoked grass every day, mate. … I've been looking after myself, mate [PD2].

> I train every day. I do cardio training and weight training. … Treat your body like a temple, not a nightclub, you know? [PD5].

Self-preservation

As patients experienced many positive outcomes as a result of their engagement with HCV treatment, they reported that they would avoid any risk of re-exposure to HCV, describing it as 'a horrible thing'. Patients reported that they had developed the skills to avoid risky behaviour and protect themselves from viral exposure.

> It is about me now, …., it's about self-preservation … so it's just learning how to say no to myself and when you learn to do that, don't you, you can say no to others easier. … I've got to the stage now, mate, where I can say no,… he's [friend] always smoking it, he always just offers it to me, 'Do you want a turn, bro?' I'm just like, 'No, I'm right, mate,' and he gets self-conscious [PD2].

The self-protection was also related to a sense of responsibility towards the services that they had received during their HCV treatment.

> I appreciate it. I'm very grateful, so I respect that. I wouldn't go and reverse it and start using drugs again. No. It puts your life on a good track, you know? … I like the man I am today, and I wouldn't destroy it. … I don't pick up that first one. That's to keep on living well [PD5].

Desire to help other patients

A desire to help other patients to receive treatment was reported by some of the participants in this study. This was connected to their experiences of the services that they received and their perceived health outcomes.

> I encourage people you know? … I brought a friend in … I've encouraged him to get it done. He's getting his blood and the process happening. … Hopefully, I can drag a few more in [PD5].

> I just say to people I know on the street, other users [drug users], … 'you don't have to feel shame about it bro. Let's work together.', you know what I mean? …, they've listened to me and come and got treatment [PD2].

Discussion

The patients interviewed in this study reported improvements in their physical and mental health, including improved level of energy, mood, general wellbeing, increased hope and optimism, and dispelled or reduced shame and fear of long-term sequelae. Patients also expressed a resolve/desire to commit to healthier behaviours/lifestyle, specifically to avoid behaviours that could lead to re-contracting HCV. As well as these improvements in their own health, patients were keen to engage friends/others in treatment.

Patients reported that they had more energy after receiving HCV treatment. Fatigue is the most frequent extrahepatic manifestation in people with chronic HCV, and predicts poor health-related quality of life (Golabi *et al.* 2017). Although it has been reported that a majority of patients do not experience any symptoms related to HCV (Treloar *et al.* 2014; Madden *et al.* 2018*b*), it needs to be considered that many patients have several comorbidities such as mental illness and substance use problems that may affect their perception of symptoms (Sylvestre *et al.* 2004; World Health Organization 2016). This may also be exacerbated in the clinical environment, where patients' day-to-day experience of fatigue and lethargy may be neglected, and the emphasis is on preventing patients from developing hepatocellular carcinoma (Golabi *et al.* 2017). Advocating 'feeling more energetic' as an outcome of treating HCV may help patients to understand the immediate and tangible benefits of initiating and adhering to HCV treatment (Richmond *et al.* 2018), aside from the long-term reduction in the risk of developing severe liver-related and extrahepatic disease (Lingala and Ghany 2015; World Health Organization 2018).

Access to curative DAA drugs helped patients to develop a sense of hope for a better and longer life. Awareness of life-threatening consequences of HCV often makes patients feel hopeless and anxious about their future (Dowsett *et al.* 2017; Richmond *et al.* 2018). This highlights the importance of improving patients' awareness of the availability of effective and tolerable therapy and the associated rate of initiation of HCV treatment (Treloar *et al.* 2014; Madden *et al.* 2018*b*). It is important that in patient–provider conversations, the natural history of HCV infection, the expected outcomes of treating HCV and requirements for further monitoring after treatment (based on the patient's stage of HCV infection) be fully discussed.

Patients also emphasised that HCV treatment meant removing a source of shame and stigma. Many HCV patients suffer from internalised stigma and shame, which are related to the infectious and blood-borne nature of HCV disease and its connection with injecting drug use (Madden *et al.* 2018*a*, 2018*b*; Richmond *et al.* 2018; Wright *et al.* 2019; Pourmarzi *et al.* 2020). Experiencing stigma from society and the health system often makes it difficult for patients to engage socially and access health services, and thus leads to marginalisation in this group (Treloar *et al.* 2014; Richmond *et al.* 2018; Garvey and Jones 2019). Patients may also see themselves as 'agents' of infection, with negative consequences for their mental health, including anxiety about their family members' health (Madden *et al.* 2018*a*; Richmond *et al.* 2018). Understanding the social aspects of HCV infection and patient-experienced illness can be helpful for supporting patient-centred HCV treatment and improving patients' quality of life.

Study participants reported that, as a result of the treatment they received and associated improvements in physical and mental wellbeing, they were looking after themselves and engaging in protective behaviours to minimise the risk of re-infection. Incorporating prevention and health promotion in HCV treatment is a cornerstone of HCV elimination (Hajarizadeh *et al.* 2016). With consideration of patients' characteristics and the barriers that they experience accessing health services, for many patients initiating HCV treatment is a big step, which shows their motivation to change their lifestyle (Madden *et al.* 2018*b*; Richmond *et al.* 2018; Pourmarzi *et al.* 2020). Curing HCV is an important focal point, which can create opportunities to empower patients to practice healthy behaviours, thus improving their quality of life. It should be considered that many patients suffer from multiple comorbidities, including mental health problems, and lack of social stability (Sylvestre *et al.* 2004; World Health Organization 2016). Consequently, improving patients' quality of life needs a multidisciplinary approach to address the whole person not just the HCV (Pourmarzi *et al.* 2019*b*).

The desire to help other patients to initiate HCV treatment was another outcome reported by patients in this study. This type of outcome was also reported in previous studies (Batchelder *et al.* 2015; Richmond *et al.* 2018). The experiences associated with being cured motivates patients to encourage their friends and peers to initiate HCV treatment. Apart from the tolerability of medications, patients' experience with healthcare providers is an important predictor of the acceptability of HCV treatment (Pourmarzi *et al.* 2019*d*). Patients' desire to help others and increased social capacity present opportunities for engaging with hidden populations of patients with HCV infection who are an important target group for HCV elimination (Hajarizadeh *et al.* 2016).

Strengths and limitations

This study is one of the first during the DAA era to explore patients' perceived outcomes of engaging in HCV treatment. We used a qualitative approach to develop an in-depth understanding of patients' experienced outcomes. Some of the participants were receiving counselling for their substance use problems or were using other services, which may have a positive effect on their experience of HCV treatment. The qualitative nature of this study limits the generalisability of findings to other settings and populations.

Conclusion

Findings from this study indicate that patients expect and experience various outcomes of HCV treatment, which are related to physical, psychological and social aspects of living with, and being cured of HCV infection. Patients may experience improved physical and mental health and positive changes in their behaviour and social interaction during and after HCV treatment. Understanding patients' feelings and ideas about HCV, the ways HCV affects their functioning, and their expectations of seeking treatment can provide an opportunity to

treat the whole person. As many patients do not experience any symptoms attributable to HCV, interpretation of clinical outcomes (i.e. sustained virologic response) in a way that is understandable and tangible for patients and which emphasises the effects of HCV treatment on psychological and social aspects of patients' daily life, may improve patients' engagement with HCV treatment. These also need to be considered in professional and public awareness programs advocating to improve treatment uptake; those who have had personal experiences of treatment and being cured are well positioned to articulate these messages and could contribute to advocacy for improving treatment uptake.

Conflicts of interest

The authors declare no conflicts of interest.

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