In recent years, eligibility criteria for hepatitis C treatment have expanded. At the same time, the management of side effects and the efficacy of treatment have significantly improved. However, the number of people with hepatitis C who agree to undertake and then complete the treatment regimen remains alarmingly low.

Barriers to starting and completing hepatitis C treatment

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There are many reasons that people with hepatitis C may not start nor complete treatment.

Factors relating to treatment

The treatment of hepatitis C, generally with the antiviral agents pegylated interferon and ribavirin, is associated with a significant risk of adverse side effects, such as the suppression of bone marrow production, anaemia, depression and other mood disorders, fatigue and nausea, which lead approximately 14% of recipients to discontinue treatment (Manns et al., 2001). Ribavirin may lead to birth defects, so people contemplating pregnancy often defer treatment (Yee et al., 2006). The most common reason for deciding not to take up hepatitis C treatment or for discontinuing it is that it commonly has psychiatric effects that many find intolerable (see Summary 4). Because treatment generally takes 24 to 48 weeks, people who do not have access to transport, or are transient, homeless and/or engaged in criminal activity may not complete it (Restrepo et al., 2005). In many places treatment is costly and therefore unaffordable for some. As well, there might be insufficient refrigeration facilities for the required storage of interferon.

Personal factors

Homelessness, cognitive deficits, exposure to violence, lack of social support, poor economic status, inadequate knowledge of hepatitis C and its treatment, current substance use, having other health conditions, and negative past experiences with health care practitioners are known to have negative effects on the uptake and continuation of hepatitis C treatment (Corsi et al., 2007). Distrust of health care practitioners is a common reason for not beginning or continuing treatment (Hopwood & Treloar, 2005). People may perceive having hepatitis C as a lesser priority than other aspects of their life, particularly when they are asymptomatic (see Summary 1), and may thus avoid treatment.

Social factors

Peers who tell ‘horror stories’ of side effects or the ineffectiveness of treatment may influence others to defer or avoid treatment, contrary to doctors’ advice (see Summary 2). Doctors may inadvertently discourage people from starting treatment by commenting that hepatitis C is unlikely to cause them much concern or that the treatment is unlikely to be effective (see Summary 3). Doctors may not offer hepatitis C treatment to people with addictive or psychiatric disorders if they believe that the person will be at risk for depression or suicide and/or will not comply with treatment protocols (Doab et al., 2005). Numerous studies have demonstrated that people who have stable psychiatric disorders and/or a history of substance use are likely not to experience more depression, and their adherence to treatment is equal to or greater than that of the general population with hepatitis C (Pozza, 2007).

Structural factors

In many countries hepatitis C treatment is provided largely by doctors in urban liver clinics. People from rural or remote communities who must travel to a city clinic may not be able to participate in treatment, particularly if they live in poverty or lack transport. Prisoners may not receive access to hepatitis C treatment partly due to the stigmatisation of people with hepatitis C that is common in prisons, but also because there is often a lack of resources in prisons to support care for those with hepatitis C (Weinbaum et al., 2003). Some drug addiction and psychiatric clinics offer hepatitis C treatment to their patients (Strauss et al., 2007) but people who do not want the services provided by the clinic, or who fear that their drug use or psychiatric disorder will be exposed if they attend, will not go to such clinics for treatment (McLaren et al., 2008).
Encouraging more people to take up treatment

Evidence supports the use of integrated, multidisciplinary models of care to encourage people to take up and then complete hepatitis C treatment (Geppert & Arora, 2005). Levels of uptake of treatment have been improved in programs that shift treatment from specialty to primary care clinics that provide intensive education for health care practitioners and social support for patients by peers and/or a multidisciplinary team (Krook et al., 2007). Some preliminary evidence points to the modest use of cannabis (Sylvestre et al., 2006) as beneficial in assisting injecting drug users to adhere to hepatitis C treatment.

References


In a recent study of injecting drug users who had tested positive for hepatitis C, more than half had been offered treatment but only a fraction had taken it up. This was despite the fact that over 75% of those who had never been treated said they would be willing to have treatment.

Canadian researchers Grebely et al. surveyed 188 injecting drug users, all of whom were hepatitis C positive, about their willingness to receive treatment for hepatitis C and why they didn’t take it up. All were recruited from two urban community clinics that provided multidisciplinary primary care mainly to marginalised populations in a core area of a Canadian city.

More than half (56.9%) of the research sample reported that they had never requested hepatitis C treatment although many (51.1%) had been offered it. Three-quarters (76.5%) of those who had never received treatment indicated that they would be willing to take it up. The participants identified barriers to treatment that have been determined by other studies, i.e. lack of information about treatment, the perception that treatment was unnecessary because they had no symptoms, and the fear of adverse side effects.

At first glance, this research seems to contribute few new findings beyond the participants’ reported willingness to engage in treatment. However, it offers insights that are apparent only when one considers the nature of the sample population. The participants in this study demonstrated a commitment to their health, as they had sought health care at the clinics. The clinics appeared to be exemplary in their multidisciplinary, integrated model of care and commitment to marginalised populations. Even so, only 16% of the participants had taken up treatment, which was far from ideal (although this proportion was higher than has been reported elsewhere) and the same barriers predominated as have been reported elsewhere. This suggests that the issue of low uptake of treatment is much more complex than the types of approaches used by health care practitioners in their interactions with people with hepatitis C. It highlights the need for creative and effective dissemination to people with hepatitis C on the need for treatment and its availability. As well, it points to the need for advocacy, changes in practice, and development of policy that result in the provision of information and support to people making decisions about hepatitis C treatment. For example, there needs to be a tool to help someone with asymptomatic hepatitis C understand the implications of not engaging in treatment.

2 What influences decisions about hepatitis C treatment?

In a study by US researcher Munoz-Plaza and colleagues, individual and focus group interviews were conducted with patients at 14 drug treatment centres across the US about the factors that influenced their decision to take up, defer or avoid hepatitis C treatment. Participants’ decisions not to participate in hepatitis C treatment were largely influenced by negative information received from peers, particularly about the side effects of treatment. Other factors that led them to avoid treatment were the perception that they did not need treatment and the belief, often reinforced by health care practitioners, that the diagnosis of hepatitis C was not as serious as a diagnosis of HIV. Positive influences on the decision to take up treatment were knowledge of the disease and its consequences, experiencing debilitating symptoms, and peers who conveyed optimistic messages about hepatitis C treatment. Participants expressed a desire to be given information about the pros and cons of hepatitis C treatment before they made the decision whether or not to take it up. The study highlights the importance of peer networks and mentors as both negative and positive influences in the decision to participate in hepatitis C treatment.


3 To have or not to have treatment? What to consider

This study by Fraenkel et al. is unique because it was the only one found that extended the discussion of barriers to treatment to explore how people actually arrived at the decision to have or not to have treatment. The research findings presented some participants’ decision-making processes as involving making a ‘trade-off’ between the perceived short-term risks of toxicity and the tentative long-term benefits of hepatitis C treatment. This process was determined by the meaning and value that the person ascribed to the risks and benefits. Other participants did not consider anything other than having the treatment because of the negative experiences of peers who did not have it or because their doctor told them it was necessary. Some people chose not to begin hepatitis C treatment because of the fear that side effects might make them unable to work or might damage their interpersonal relationships. The study demonstrates the importance of holding discussions with patients about what they believe and value before offering them hepatitis C treatment.


4 Can people be truly prepared for the side effects?

Treloar and Hopwood raise an interesting issue that has not been widely explored. If, in discussion with a health professional before hepatitis C treatment begins, people are unrealistically optimistic about their ability to cope with treatment, what happens to their motivation and ability to adhere to it when they encounter debilitating side effects? The perspectives of people who had completed or discontinued hepatitis C treatment, and those of health care providers, contributed insights into how people who are unrealistically optimistic tend to have confidence in their ability to cope, based on their past experience in dealing with physical and psychological challenges. They tend to disregard as irrelevant the information provided about possible side effects. When they then encounter the debilitating side effects of treatment, they do not immediately recognise that they are not coping and thus delay asking for assistance. The research provides strong support for a model of hepatitis C treatment that includes ongoing monitoring and support from the health care team.


continued overleaf
Barriers to receiving hepatitis C treatment

In Australia, 224 people with hepatitis C responded to a 78-item questionnaire that explored their demographics, overall health, and experiences with diagnosis, testing, health care and treatment. Participants included those currently receiving treatment for hepatitis C ($n = 45$), those who had received treatment in the past ($n = 65$) and those who had not received treatment ($n = 114$). One of the most interesting findings of this research was that distressing side effects of treatment, particularly depression, were the primary reason for people’s decisions to defer, discontinue or avoid treatment. Even people who had never had hepatitis C treatment rated side effects as their greatest concern about undertaking it. Another significant fear was of liver biopsy. This speaks to the need for better dissemination of information about how side effects, as well as the pain and risks associated with liver biopsy, can be managed. It also suggests the need for additional research to investigate how people develop such fears and whether or not there are strategies that could effectively mediate them.


More treatment for people with mental illness

Goldberg and Seth’s pilot study evaluated the effectiveness of a program to improve case management by service providers to prevent hepatitis C transmission, and manage and treat the infection, among people with hepatitis C and serious mental illness (i.e. schizophrenia spectrum, or bipolar or psychotic disorder). Service providers were intensively educated on case management, how to put clients in touch with community services, and best practices in caring for people with hepatitis C. They were also given the blood-test results of the people enrolled in the study and encouraged to provide appropriate follow-up to those who tested positive. The results indicate that many people with serious mental illness who are infected with hepatitis C, even those with access to regular care, are not receiving appropriate medical follow-up, particularly information about the possibility of hepatitis C treatment. This begs the question: why, if there are national guidelines stating that hepatitis C treatment can be offered to people with psychiatric disorders on a case-to-case basis, do many practitioners not implement these guidelines? Further, it suggests a need for strategies to effectively address practitioners’ fears about providing treatment for this population.


Injecting drug users who don’t get treatment

This Canadian study by Moirand et al. was a retrospective review of the charts of injecting drug users who were patients in an urban liver outpatient clinic. The findings revealed that only 38% of eligible patients completed hepatitis C treatment; a significant number refused treatment or were lost to follow-up. Interestingly, the majority of patients ‘dropped out’ of the clinic soon after their initial visit. This was after the patients had met with their primary care doctor, were referred by the doctor to the clinic and then waited six to eight months for an appointment at the clinic. This finding has been documented in other research. It suggests either that the person was unprepared for their first visit to the liver clinic and the information they received, or that the first visit was not supportive nor instructive enough to convince them to begin treatment. It may also relate to Treloar and Hopwood’s finding that people can be unrealistically optimistic until they are confronted with the realities of the challenges they will face; perhaps the first visit to the liver clinic represents such a confrontation.


Relevant websites


Hepatitis C Council of NSW: downloadable pdfs of resources to assist people contemplating, receiving, or who have completed, hepatitis C treatment. See http://www.hepatisc.org.au/resources/AHCresearches.html


National Hepatitis C Prison Coalition, USA, recently advocated for inmates co-infected with HIV not to be excluded from treatment for hepatitis C. See http://www.hcvinprison.org/cms/index.php


Hepatitis C Action Plan for Scotland: includes evaluations of initiatives to increase the uptake of hepatitis C treatment. See http://www.hepcscotland.co.uk/action-plan.html