Do doctors understand what helps patients with hepatitis C stay on and complete their treatment?

To be cured of hepatitis C, patients must take their medications as prescribed without missing doses and complete the full course of treatment. However, almost half of patients with hepatitis C find it difficult to take their medication regularly due to problems with side effects, homelessness, not having enough friends and/or family to support them, or feeling the need to hide their disease at work.

To find out what types of psychological and social problems make staying on treatment most difficult for patients, we interviewed 10 doctors, 10 nurses, and 20 patients to ask them what they believed kept patients from being able to take their medication regularly and finish their treatment, and alternatively, what was most helpful for patients.

We then compared the doctors' and nurses' responses to the patients' to find out if healthcare professionals had the same viewpoints as patients, or if they disagreed in some areas.

We found that communication between patients and healthcare professionals (doctors and nurses) was a problem for some of the patients. Some doctors felt that patients would get confused if they gave them too many details on hepatitis C or their treatment, and patients said they felt resentful that they were denied important information about their treatment, and that not receiving this information from doctors implied that they saw these patients as unintelligent and unable to understand.

Patients, doctors and nurses agreed that healthcare professionals who are rushed are less likely to give their patients enough information and more likely to have poor communication. Heavy workloads and time pressures were mentioned as problematic for nurses and doctors who felt that the busy clinic environment prevented them from being able to give better care to their patients.

There was also agreement that clinical feedback was helpful to patients. Clinical feedback is when doctors and nurses discuss treatment plans and medical results with their patients. Patients wanted to know their medical results, such as liver enzyme levels and viral load. Doctors and nurses felt that patients were more motivated to stay on treatment when they were shown positive progress, but patients said that it was important to them to know how they were doing regardless of whether the results were positive or negative.

Patients with hepatitis C experience stigma – a feeling of being disgraced – because it is a disease you can get from injecting drugs. Patients reported that the feeling of being stigmatised, or being discriminated made it difficult for them to tell their friends, family, and co-workers about being infected with hepatitis C. One doctor spoke about a patient who was bullied at work because his co-workers found out he had hepatitis C and it led to him stopping his treatment.

Finally, the healthcare system itself can make it difficult for patients to continue and complete their treatment when patients have long waits in clinics that keep them away from work, rushed visits with doctors and nurses, and see different doctors each time they visit the clinic, some of whom provide patients with conflicting information.

This study highlights the need for programs to be developed that help reduce stigma, improve communication between doctors and patients, and address the limitations of the clinic environment, such as time pressures and continuity of care (patients being able to see the same doctors who provide consistent information) so that patients with hepatitis C can be get the help they need to stay on and complete treatment and have a better chance of being cured.

Victoria A. Sublette
The University of Sydney
Australia The Westmead Institute for Medical Research
Australia Westmead Hospital, Australia

Publication

Listening to both sides: A qualitative comparison between patients with hepatitis C and their healthcare professionals' perceptions of the facilitators and barriers to hepatitis C treatment adherence and completion.
Sublette VA, Smith SK, George J, McCaffery K, Douglas MW.
J Health Psychol. 2016 Feb 8