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Hepatitis C-related information on the internet: perspectives of people with hepatitis C

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INTRODUCTION

Interview data from a quantitative and qualitative research project explores how people with hepatitis C use print- and internet-based information sources. Internet access allows resources and information that were previously accessed almost exclusively by health professionals to be available to the public. This challenges traditional modes of information provision in clinical encounters. While medical literature reflects concerns among health professionals about the quality of online health information, little empirical research addresses the practices and perspectives of health consumers.

METHOD

People with hepatitis C who responded to a national online survey about their use of the internet to access hepatitis C-related information were asked to volunteer for a follow-up face-to-face semi-structured interview. Twenty people, from NSW, VIC and WA, were interviewed.

INTERVIEW DATA

The quotes below illustrate the following characteristics of internet use by people with hepatitis C:

- when first diagnosed, comprehensive and broad searches for anything relating to hepatitis C

  You've got to fill your head with as much information as you can. (Ray)

- focused searches and a tendency to stick with familiar and trusted sources

  I went to a lot of websites and had a look … but I soon sort of sorted them out. (Jonas)

  So you go lookin' through those and see what sort of links they have … and eventually you get back to some *really* good sources of information. (Ray)

- a strong preference for Australian websites

  My main one at the moment is NSW Hepatitis C Council. I found them to be the best. You know, it's local … found out that they were the most informed. (Wayne)

  … looking to reputable and certainly Australian-based sources for that was important for me. (Fiona)

- internet use in conjunction with information from health professionals

  You talk to your doctors, they haven't got the time to explain it to you. (Wayne)

  … one of the things I like about the internet is that you can go searching for the level of complexity that you can cope with. (Fiona)

  … that's sort of what I understand from reading different things on the internet. When he explained it to me, I couldn't make head nor tail of it. (Michael)

  If he said something that I didn't quite understand … I'd check it up later … Like the internet's got to be a bonus for 'em because … if I can find out information myself and get them to confirm anything I've got my doubts about … (Wayne)

  I think it's good that they have that chat night with professionals. (Nicola)

- the value of interaction.

  If it was something that had, you know, quite judgmental tones in it, I wouldn't read it. I might respond to it and sort of talk to them about their attitudes or something. (Gaby)

  But what was really good about it is that if you said something, if it wasn't right, people would come back and go, 'No, but this research shows this and this research shows that'. So, rather than like a web page, where people can just put up what they want and no one can dispute it … I actually thought that that was almost the most accurate way, because it was like a public debate in a way. (Fiona)

  I think it would have been very isolated if I didn't have internet when it came to hepatitis C … Everybody who get hepatitis C, they should get a computer from the government. (Jonas)

DISCUSSION

The internet is already being used by people with hepatitis C. More research is needed to understand how it is used and how this can be deployed to optimise health outcomes.

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