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Consumer health information seeking: strategies and perspectives of people with chronic illness

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INTRODUCTION

This presentation is based on interview data from a quantitative and qualitative research project exploring the use of print- and internet-based information sources by people with hepatitis C. Traditional modes of information provision within clinical encounters have been altered by public internet access to resources and information that were previously accessed almost exclusively by health professionals. While medical literature raises concerns among health professionals about the quality of online health information, little empirical research addresses health-consumer practices and perspectives.

METHOD

A national online survey was conducted to discover how people with hepatitis C used the internet to seek information relating to their illness and how they then made use of this information. Those who responded to the survey were asked to volunteer for a follow-up, face-to-face, semi-structured interview. Twenty people, from the Australian states of New South Wales, Victoria and Western Australia, were interviewed.

DISCUSSION

There is a need for greater understanding among medical and information professionals of lay capacities to collect, understand and act upon information from the internet. Unlike people who use the internet for occasional health information, many people with chronic illness develop, over time, complex strategies for accessing, evaluating and applying online information.

INTERVIEW DATA

The following quotes, under various categories, exemplify information-seeking and -use practices of 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)
I was hungry for information. (Fiona)
- 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 local 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)
- strategies for judging the value of information sources
If you go to proper studies, the criteria is all down the bottom of what they've done ... then you can pretty well rest assured that they will be correct ... but where it's just sort of like a text page and there's no references to anybody, or references to who did the study ... you

generally just wipe them. You'll read just to see what they're saying, you know. (Ray)

... if it's from a journal ... if I find some information, I'd like to know where it comes from ... anything that I read from the Hep C Council, I tend to take it that it's right. (Nicola)

But if you go to a dozen sites and nine of them are saying the same thing, well you assume that they're pretty right ... going to multiple sites ... that information's here, they're saying the same thing here, same thing there, then you take it as being, pretty ... right. (Tim)

- use of information from the internet in conjunction with information from health professionals
... 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)
- the value of interaction
I think it's good that they have that chat night with professionals. (Nicola)
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 don't really have to go reading medical journals 'cause there's that many people that do it and if there's anything interesting or that's going to impact on anybody we hear about it just about as soon as it's been brought out ... I'd say it'd be very hard for anything to get past ... there's some great people, you know, that I s'pose have proved themselves over the time that their information's good, so you do trust ... I think if anybody put anything on there that you couldn't believe, somebody'd pick it up in about two seconds flat because you've got people who do that all the time ... and some of that stuff in the journals is really wordy, and it's great when there's people around that can, sort of, decipher that and put it down ... for everybody. (Andy)

- applying the information acquired from the internet to everyday situations.
You're sort of piecing these bits of information to really realise how it's impacting on your future, because your vision of the future changes. So, you've got to try and incorporate this new information to what you thought your future was going to be. (Fiona)

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