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Shared knowledges, communications and decisions about chronic illness: perspectives of people with hepatitis C

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INTRODUCTION

A quantitative and qualitative research project explores the use of print- and internet-based information sources by people with hepatitis C. Twenty participants were interviewed about their experiences of information-sharing in everyday and clinical settings, including about conditions that enable information to be exchanged, discussed and incorporated in processes of shared decision-making. In part, the interviews highlighted some obstacles to effective communication between health professionals and people with hepatitis C.

BACKGROUND

■ Shared decision-making

'Partners work together to achieve common goals. Their relationship is based on mutual respect for each other's skills and competencies ...' (Coulter 1999, p. 719)

■ Hepatitis C and discrimination

With approximately 80% of infections in Australia associated with injecting drug use, hepatitis C is a highly stigmatised illness. A recent enquiry found that relationships between people with hepatitis C and health professionals were seriously compromised by discrimination in health care settings and that such discrimination deters people from seeking appropriate treatment and care (Anti-Discrimination Board of NSW, 2001).

'One of the biggest problems for drug user groups is that by the time an individual receives a hepatitis C diagnosis they are so imbued with the negative responses and overt discrimination due to their drug use ... The expectation then is that such attitudes within the health care/medical community will continue in the context of future treatment.' (Byrne 2002, p. 7)

DISCUSSION

Given the prevalence of negative experiences and expectations in relation to health service provision, health professionals cannot assume the trust of people with hepatitis C. Relations of partnership, necessary for shared decision-making, require non-discriminatory contexts in which health professionals honour the personal integrity, as well as the skills and competencies, of patients. Such conditions facilitate the information exchange, dialogue and discussion necessary for shared decisions about treatment to be made.

References

- Anti-Discrimination Board of NSW (2001). *C-change: Report of the enquiry into hepatitis C related discrimination*. Sydney: Anti-Discrimination Board of NSW.
- Byrne, J. (2002). Discrimination in health care settings: Injecting drug users and hepatitis C. *Australian Hepatitis Chronicle*, 11, 7–8.
- Coulter, A. (1999). Paternalism or partnership? *British Medical Journal*, 319, 719–720.

INTERVIEW DATA

▶ The radiographer asked me why I was having [the ultrasound]. I said 'hep C' ... I felt like she just gave me a really dirty look and I felt like her attitude changed towards me. And I was thinking, right, she should know better ... I think it's because everyone sees it as being only with injecting drugs. (Michael)

▶ ... generally, drug users don't like going to the doctor or the hospital or whatever, so they'll just go – and probably because of discrimination, those kind of issues ... even if they're getting quite sick from it – they'll just go, 'Ah, it's not too bad'. (Gary)

▶ ... when you go to the dentist they ask you whether you've got hep C or not ... most people will say 'no', anyway, because once you say 'yes' you can't get in there, and they suit up ... A lot of the times it's just a hell of a lot easier not to disclose it, just so you don't get the discrimination. (Andy)

▶ There's so many people who were intimidated by their doctors, and a lot of people that were treated poorly by their doctors ... if you don't like your doctor, go – go find one until you do ... It's worth seeing ten in six months, so that you've got someone that you can talk to, and who will answer your questions, who won't, you know, look down their nose at you, or treat you like a moron. (Fiona)

▶ I'm more comfortable in these places [drug user health services] ... you're with your peers, so to speak, no judgement – like, you go to a lot of medical practitioners and things and they'll still, you know – in this modern day and age – there's still a little bit of prejudice, or just like, distaste at least ... I usually seek places out like this so I get me peers to help me. They understand. (Peter)

▶ ... the staff are wonderful and really non-judgmental ... I've got such a good relationship with this doctor – I've seen him every week for five years – I feel comfortable enough to ask him – like I don't have any problem discussing anything with him ... Whereas with the GP, I feel really on guard with her, and there would be a lot of things that I don't ask her, that I would take to my specialist doctor ... If I don't understand I say, 'What does this mean?' ... And he looked at the results and said, 'Oh I think you're – you're drinking heavy aren't you?' Like he sort of knows and I go – 'Yes, I am.' So, you know, I sort of mention those things like that and we discuss things like that. (Nicola)



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