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Review

Views and experiences of hepatitis C testing and diagnosis among people who inject drugs: Systematic review of qualitative research

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ABSTRACT

Background: Many developed countries are facing a major challenge to improve identification of individuals acutely and chronically infected with hepatitis C virus (HCV) infection. We explored the views and experiences of people who inject drugs (PWID) in relation to HCV testing, and diagnosis through a review and synthesis of qualitative research.

Methods: Based on the thematic synthesis of qualitative research. Searches were conducted in 14 databases and supplemented by reference checking, hand searching of selected journals, and searches of relevant websites. Studies of any qualitative design that examined the views and experiences of, and attitudes towards, HCV testing and diagnosis among PWID or practitioners involved in their care were included. Key themes and sub-themes were systematically coded according to the meaning and content of the findings of each study which proceeded to the preparation of a narrative account of the synthesis.

Results: 28 qualitative studies were identified. We identified a number of overarching descriptive themes in the literature, finding overall that PWID hold complex and differing views and experiences of testing and diagnosis. Three major themes emerged: missed opportunities for the provision of information and knowledge; shifting priorities between HCV testing and other needs; and testing as unexpected and routine. Evidence of missed opportunities for the provision of knowledge and information about HCV were clear, contributing to delays in seeking testing and providing a context to poor experiences of diagnosis. Influenced by the nature of their personal circumstances, perceptions of the risk associated with HCV and the prioritisation of other needs acted both to encourage and discourage the uptake of HCV testing. Undergoing HCV testing as part of routine health assessment, and an unawareness of being testing was common. An unexpected positive diagnosis exacerbated anxiety and confusion.

Conclusion: This review has identified that there are modifiable factors that affect the uptake of HCV testing and experiences of HCV diagnosis among PWID. Intervention development should focus on addressing these factors. There is a need for further research that engages PWID from a diverse range of populations to identify interventions, strategies and approaches that they consider valuable.

Introduction

Worldwide, around 150 million people are chronically infected with the hepatitis C virus (HCV) and injecting drug use is an important risk factor for acquiring the infection in high-income countries (World Health Organization, 2012a). HCV infection is highly prevalent among people who inject drugs (PWID), varying from around 60–80% of PWID infected across national samples in Western Europe, the USA and Canada (Nelson et al., 2011). Early diagnosis of HCV provides the best opportunity for effective medical support and the prevention of further transmission (Corey, Mendez-Navarro, Gorospe, Zheng, & Chung, 2010). However, despite the high burden of disease associated with HCV, it is still a neglected disease in many countries and many individuals remain unaware of their HCV positive status (Volk, Tocco, Saini, & Lok, 2009; Mühlberger et al., 2009). The World Health Organization has recognised the need to integrate proven public health strategies for preventing viral hepatitis across health systems (World Health Organization, 2012b). However, while effective government-led programmes to improve screening have been implemented in some European countries (for example France; Hatzakis et al., 2011), in others, including Australia (Hopwood & Treloar, 2004), the UK (Morris, 2011) and USA (Volk et al., 2009), evidence suggests continued variation in the availability and uptake of HCV testing,

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treatment, care and support services. Many high-income countries are therefore facing a major challenge to improve the identification of individuals with HCV infection. In order to inform policy and practice responses and to address questions about appropriateness and acceptability of interventions aimed at increasing HCV testing uptake, we carried out a systematic review of qualitative research. The purpose of the review was to provide a narrative perspective on how PWID view HCV testing, their experiences of the communication of test results and what they perceive as the barriers and facilitators to participation in these strategies.

Methods

This study was conducted as part of a series of extensive systematic reviews to inform evidence-based policy recommendations on ways of offering hepatitis B and C testing in England by the UK National Institute for Health and Clinical Excellence (NICE). We used established methods for the thematic synthesis of qualitative research (Thomas & Harden, 2008) to explore the views and experiences of PWID, and health professionals involved in their care, in relation to HCV testing and diagnosis. This method was chosen as it enabled us to examine research addressing questions relating to need, appropriateness and acceptability of interventions aimed at increasing HCV testing uptake and subsequently develop analytical themes that could be used to inform intervention development. The following four research questions were formulated in relation to the views and experiences of PWID, and health professionals involved in their care:

(1) What are their knowledge, beliefs and practices to HCV?
(2) What are their experiences of barriers and facilitators to HCV testing and diagnosis?
(3) What are their views, experiences and attitudes of HCV testing, diagnosis, and communication of test results?
(4) What are their views and perspectives on opportunities for changing behaviour in relation to HCV testing and diagnosis

Literature searching

We utilised a combination of strategies to locate evidence for the review, including searching electronic sources, reference checking of included studies and key review articles, hand searching of selected journals, and searches of relevant websites. A detailed search strategy was developed for 14 databases using a combination of free text and thesaurus terms for HCV combined with free text and thesaurus terms for qualitative methods, and population or social factors (see the example search strategy in the e-only Supplementary files). Searches were conducted in March and April 2011 and limited to studies published since 1990. Following the initial screening of titles and abstracts, potentially relevant references were examined to identify the five journals with the highest yield of references (Australian Health Review, Gastroenterology Nursing, International Journal of Drug Policy, Journal of Community Health, and the Journal of Viral Hepatitis). All journal issues (and supplements) published between 2008 and 2011 were hand searched comprising a total of 113 issues.

Study selection

Two reviewers from a team of four (LJ, EMC, GB and LP) independently screened 6255 titles and abstracts retrieved from the database searches according to the inclusion and exclusion criteria described. Based on title and abstract screening, 285 potentially relevant articles were identified and screened by two reviewers independently from the same team of four. Hand searching identified a further 36 articles but after removal of duplicates only one article was potentially relevant. No further relevant articles were identified by checking reference lists or review articles. We included studies of any qualitative design, including the qualitative elements of mixed methods research. We excluded studies that focused solely on general population groups or other groups at risk of HCV infection where it was not possible to attribute the findings to current and/or former PWIDs, studies that included only HCV/HIV co-infected individuals and studies that used structured questionnaires as the sole method of data collection or that reported only quantitative data. A summary of study identification is provided in a flowchart within the e-only Supplementary files.

Thematic synthesis

Verbatim findings of the included studies were extracted with brief information about the study methodology. Key themes and sub-themes were coded line by line according to the meaning and content of the findings of each study using NVivo 9 software. Coding of each study was undertaken by one reviewer (AA) and a second reviewer (LJ) checked the consistency of the key themes and sub-themes that emerged by reference to a random subset of the studies identified for inclusion. Two reviewers (AA and LJ) independently assessed the quality of the individual studies in accordance with Methods for the development of NICE public health guidance (National Institute for Health and Clinical Excellence, 2009). By examining the findings of each included study, descriptive themes were independently coded by one reviewer. Once all of the included studies had been examined and coded, the resulting themes and sub-themes were discussed as a team (AA, LP and LJ). The qualitative synthesis then proceeded to the development of descriptive themes and analytical themes (Thomas & Harden, 2008), which were interpreted by the wider review team (AA, LP and LJ). In addition, two reviewers (AA, LJ), first independently and then in discussion, reconsidered the findings of the qualitative synthesis to draw out clear implications for intervention development in the context of the four overarching research questions. A narrative account of the synthesis was prepared and quotations taken directly from the included studies were used to support the analytical and descriptive themes discussed.

Results

Twenty-eight studies were identified for inclusion (Table 1). The majority of studies included people who had acquired, or were at risk of acquiring, infection though injecting drug use; one of which focused on people in, or recently released from, prison (Khaw, Stobbart, & Murtagh, 2007). Two studies included the views of health professionals involved in the care of PWIDs; one as the sole study participants (Perry & Chew-Graham, 2003) and one, in addition to the views and experiences of PWID (Munoz-Plaza, Strauss, Astone, Jarlms, & Hagan, 2004). Most studies specifically examined views and experiences in relation to HCV infection only, though two studies (Gyarmathy, Neaigus, Ujhelyi, Szabo, & Racz, 2006; Lally, Montstream-Quas, Tanaka, Tedeschi, & Morrow, 2008) explored viral hepatitis infection more broadly alongside sexually transmitted infections such as HIV (Table 1).

The included studies covered testing and the impact of diagnosis, including barriers and facilitators to testing, experiences of testing, reactions to diagnosis, and the impact of diagnosis on behaviour, and stigma as a barrier to testing uptake and disclosure. Our review identified a number of overarching descriptive themes in the literature, finding overall that PWID hold complex and differing views and experiences of testing and diagnosis. Three major themes emerged from the analysis of the descriptive themes: