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Using qualitative data, people's perceptions, and the science of decision making to inform policy and improve hepatitis C care for people who use drugs

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Jones et al. (2014) make an important contribution in their recent systematic review of qualitative research on how persons who inject drugs (PWID) perceive hepatitis C virus (HCV) screening and diagnosis. Systematic reviews are increasingly utilized to inform best practice guidelines and health policy (Lavis, Posada, Haines, & Osei, 2004; Sweet & Moynihan, 2007). Most syntheses of existing data focus on randomized controlled trials and quantitative data, and few make use of the equally important information to be derived from well-organized syntheses of high-quality qualitative research (Hayden, Côté, & Bombardier, 2006; Jack, 2006). The UK National Institute of Health and Clinical Excellence (NICE) efforts to inform evidence-based policy based on qualitative as well as quantitative data set a standard that should be more broadly disseminated.

HCV is a global public health problem, with over 170 million people infected (Aceijas & Rhodes, 2007). The development of highly efficacious HCV treatment affords the potential to cure HCV infections, and perhaps even eradicate HCV infection through improved primary prevention, screening, linkage to care, treatment, and treatment as prevention (Martin, Vickerman, Goldberg, & Hickman, 2014; Wiessing et al., 2014). Unfortunately dramatic gaps in the HCV care continuum significantly limit the population-level effectiveness of these efficacious therapies (Linas et al., 2014). Jones et al. highlight the significant variation in the availability, systems for, and uptake of HCV testing among PWID. In the US, significant attention has been focused on efforts to screen people in the 1945–1965 birth cohort (Ward, 2013) yet it is PWID who remain the core of the epidemic. Jones et al. highlight the importance of understanding the views and experiences of both current PWID, as well as former PWID, as former users may constitute an important proportion of those with undiagnosed HCV.

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Extending the scope of interest in Jones et al. to include people who use drugs by non-injection, as well as injection routes, would be highly relevant as non-injection drug use itself been associated with HCV risk (Oliveira-Filho et al., 2014; Scheinmann et al., 2007). People who use drugs (PWUD) but who do not inject are linked through social and risk networks with PWID populations where HCV prevalence may be 50–90% (Grebely & Dore, 2011; Koram et al., 2011). PWUD who do not inject have a high risk for transitioning to injection drug use. Recent initiates to drug injection have the highest risk for HCV acquisition (Hagan, Pouget, Des Jarlais, & Lelutiu-Weinberger, 2008).

One dominant theme in Jones et al. was the lack of clarity PWID had regarding HCV test results which our qualitative study of both PWUD, found as well (Jordan et al., 2013). Reactions to positive diagnoses were also highly variable ranging from unconcern or denial to anxiety. Likely central to this lack of clarity and variability in responses is the lack of consistent and clear post-test counseling messages. One relevant issue is reliance on two-step HCV testing procedures, in which an anti-HCV test is performed, and if positive, HCV viral load (confirmatory) testing is conducted, frequently in a separate location. Since 20–25% of those found to be anti-HCV positive will not have active infection, a temporal separation of anti-HCV and confirmatory testing complicates the post-test message; this is a step where many people become disengaged from care, never receiving needed confirmatory testing. Real-time confirmatory tests are in development; currently, reflex testing in which rapid antibody tests are followed immediately by (non-real time) confirmatory testing (from the same specimen) is the best strategy to minimize losses at this step in the HCV care continuum.

A main inference to be drawn from the consistent theme in Jones et al. and other studies of PWUDs (Jordan et al., 2013) is the need for well-developed post-test counseling messages, at the time of antibody and confirmatory testing, that effectively promote linkage to care and behavior change. Clear post-test counseling messages should also be developed both for those who are found to be uninfected and for those who have cleared infection. The 20–25% who spontaneously clear HCV unequivocally engaged in HCV risk behaviors and would therefore benefit from being told they were exposed, very fortunately cleared HCV, and that they are not immune and could get re-infected and develop chronic infection. This should be communicated in ways that promote both understanding and relevant behavior change, and access to interventions to reduce risks should be provided.

Qualitative data highlight that HCV-related beliefs and attitudes are influenced by situation, social context, and personal relationships (Munoz-Plaza et al., 2008). Numerous studies have shown that people make decisions, including healthcare decisions, using two distinct modes of decision-making – deliberative and experiential (Kahneman, 2003; Tversky & Kahneman, 1981). The cognitive frames and heuristic devices used in experiential thinking are often useful and may aide deliberative decision-making. However judgment heuristics may introduce cognitive biases, which may contradict deliberative decisions and lead to counterproductive decisions, potentially contributing to risk behaviors and poor healthcare engagement. Availability bias is one cognitive bias in which a single adverse example is given more emotional weight than the preponderance of data (Kahneman, 2003; Tversky & Kahneman, 1981). In our study, knowing others who experienced side effects from HCV treatment was cited by many as a reason to avoid HCV testing or avoid acting on test results (Jordan et al., 2013).

Another important theme was the anxiety and confusion introduced when testing was conducted without explicit consent (Jones et al., 2014; Jordan et al., 2013). Similar concerns emerged when we interviewed PWUD about their perceptions of genetic testing (Perlman, Gelpi-Acosta, Friedman, Jordan, & Hagan, 2015). When reasons for genetic testing were provided, PWUD were generally agreeable to genetic testing; when testing was conducted without rationale or a priori consent, it raised concerns of both discrimination and experimentation. Concerns about preserving one's autonomy of decision-making are not unique to PWUD and in fact are the basis for the movement towards patient-centered care (Barry & Edgman-Levitan, 2012).

A useful lesson from decision science is the recognition of ‘status quo bias’ in which people more commonly chose a default option; a classic example is that significantly more people voluntarily chose to be organ donors when organ donation is the default than when the default is to not be a donor (Thaler & Sunstein, 2008). The thoughtful use of default choices is increasingly considered and employed to promote healthy decision choices (Kahneman, 2003). Given vast improvements in HCV treatment regimens and the clear individual and potential populational benefits of identifying infected persons, consideration should be given to making HCV testing the default, with the option of opting out, with appropriate pre-test and post-test counseling (Li, 2009).

Both the UK Institute for Government and the Cabinet Office and the US National Institutes of Health have published reports on how to more fully utilize advances in the scientific understanding of decision-making and behavior change to inform policy (Institute for Government and the Cabinet Office, 2010; NIH SOBC Workgroup, 2009). Well-organized qualitative data of people's understanding and perceptions of HCV testing and care, and thoughtful and respectful application of decision science are promising strategies to improve HCV care, and to advance efforts to eradicate HCV, among PWUD.

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