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Structural factors that promote stigmatization of drug users with hepatitis C in hospital emergency departments

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ABSTRACT

Background: Interventions to mediate the stigmatization of people affected with HCV, particularly those who use illicit drugs, have been largely focused on changing health care practitioners' attitudes and knowledge regarding Hepatitis C and illicit drug use and these have had disappointing results. There is a need for research that examines factors beyond individual practitioners that explains why and how stigmatization of the population occurs within health care and informs interventions to mitigate these factors.
Methods: The research was intended to identify structural factors that contribute to the structural stigmatization of people within hospital Emergency Departments who are current users of illicit drugs and are HCV positive. The research had an interpretive description design and occurred in Nova Scotia, Canada. The year-long qualitative study entailed individual interviews of 50 service providers in hospital EDs or community organizations that served this population.
Results: The research findings generated a model of structural stigmatization that greatly expands the current understanding of stigmatization beyond individual practitioners' attitudes and knowledge and internal structures to incorporate structures external to hospitals, such as physician shortages within the community and the mandate of EDs to reduce wait times.
Conclusions: The research reported herein has conceptualized stigmatization beyond an individualistic approach to incorporate the multifaceted ways that such stigmatization is fostered and supported by internal and external structures.

Several researchers have identified that people who are infected with hepatitis C (HCV) are often subject to stigmatization within healthcare, particularly because HCV is often associated with illicit drug use (Butt, 2008; Butt, Paterson, & McGuiness, 2008; Crockett & Gifford, 2004; Faye & Irurita, 2003; Grundy & Beeching, 2004; Habib & Adorjany, 2003; Harris, 2005, 2009; Hopwood & Southgate, 2003; Lekas, Siegel, & Leider, 2011; Rhodes et al., 2008; Smye et al., 2011; Temple-Smith, Gifford, & Stoove, 2004; Treolar & Hopwood, 2004; Treloar, Hopwood, & Loveday, 2002). Such stigmatization is often multi-layered because of poverty, homelessness, race/ethnicity, or other factors that marginalize the person in society. People who use illicit drugs and are HCV positive are viewed by some healthcare practitioners as having a similar social location and power to those who are not HCV positive because the origins of their condition are believed to be the same; i.e., both HCV and illicit drug use are perceived as the result of self-inflicted, illegal and/or immoral activity (Smye et al., 2011). It is the identity of "addict", not the HCV status, which assumes predominance in practitioners' assessment of the deservedness of the person to care (Lloyd, 2010).

The classic definition of stigmatization is derived from the work of Goffman (1963) who defined stigma as an attribute that significantly discredits a person. Recent theorists have moved the discussion of stigmatization beyond interactions between individuals to consider how elements of power are inherent in the way stigma is socially constructed, institutionalized and reproduced with the structures of institutions (Castro & Farmer, 2005; Link & Phelan, 2006; Yang et al., 2007). The purpose of this paper is to describe and discuss the implications of the research findings of a two year study intended to identify structural factors beyond individual practitioners and specific to hospitals that contribute to the structural stigmatization of people who are current users of illicit drugs and are HCV positive. Structural stigmatization refers to the structures (e.g., policies, practices, rules, norms) of institutions or departments that intentionally restrict the access and care of particular people. Some of these generate outcomes that ultimately discriminate against these people. Marginalized populations, particularly those

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with addictions and mental health issues, have reported more discrimination in hospital Emergency Departments (EDs) than in other healthcare arenas (Ayalon & Alvidrez, 2007; Pauly, 2008).

Although the study was initially intended to investigate stigmatization within hospitals, more than 75% of the interview data pertained to discrimination specifically within EDs; this may reflect that the majority (14/23) of the hospital service providers who participated in the study were situated within an ED. It may also reflect that ED is a particularly stressful care setting for patients because of anxiety about the presenting condition and unfamiliarity with ED protocols; this often leads to negative perceptions of the care experience (Elmqvist, Fridlund, & Ekebergh, 2012). The decision to focus in the research on people who both use illicit drugs and are HCV positive was made in consultation with expert advisors on the research team (i.e., a hepatologist, a hepatology clinical nurse specialist, a physician who is an addiction specialist, and a nurse who administers ED services). They emphasized that the stigmatization of people who are HCV positive experience is directly linked to the assumption that they use illicit drugs.

Review of the literature

The pervasive nature of stigmatization of people who use illicit drugs and are HCV positive has been the focus of considerable research. Much of that body of research has investigated healthcare practitioners' attitudes or the perspectives of people who use illicit drugs and are HCV positive about the care they received from hospital practitioners. In one research study involving people infected with HCV in a hospital specialty clinic (Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003), 57% of the 257 respondents reported that they had been experienced discrimination by healthcare workers. In another study involving people who use illicit drugs and are HCV positive, the vast majority (more than 90%) of the 274 respondents recruited from community methadone clinics indicated they had experienced discrimination enacted by healthcare staff, particularly in hospitals (Habib & Adorjany, 2003). More than half (65%) attributed this to their use of illicit drugs.

There is growing evidence that current illicit drug use places the person with HCV at more risk for stigmatization within healthcare settings than people who are not currently using or have never used illicit drugs (Hopwood & Southgate, 2003). People who currently use illicit drugs and have HCV report experiencing considerably more incidents of discrimination and more dissatisfaction with the quality of care received, as well as receiving less informational, emotional and instrumental support within healthcare than do people who are HCV positive who do not use illicit drugs (Day, Jayasuriya, & Stone, 2004; Gifford et al., 2005; Habib & Adorjany, 2003; Hopwood & Treolar, 2004).

The sources of stigmatization beyond the individual practitioner are implied but not clearly explicated within the body of research about stigmatization of people who use illicit drugs and are HCV positive. For example, Stephenson (2001) suggests that institutional and departmental policies about who is eligible for HCV treatment is a structural factor that perpetuates stigmatization of people who use illicit drugs and are HCV positive, but does not address how and why these policies contribute to stigmatization within healthcare settings. Likewise, McCreadie et al. (2010) indicate that nurses' and hospitals' organizational routines challenge drug user rituals (e.g., having to leave the ED to obtain drugs means that patients lose their place on the triaged wait list for ED care), leading both patients and nurses to become angry and frustrated with the other. Institutional cultures, particularly ones that normalize stigmatization, have been identified by a few researchers as influencing whether people who use illicit drugs and are HCV positive are viewed by practitioners as deserving of care, respect and attention (Butt et al., 2008; Wright, Linde, Rau, Gayman, & Viggiano, 2003).

Research to date has assumed an individualistic focus, exploring how and why individual practitioners stigmatize people who use illicit drugs and are HCV positive. Paterson, Backmund, Hirsch, and Yim (2007) determined in a synthesis of qualitative research about stigmatization of people who are HCV positive that there are two central themes evident in this body of research: (1) stigmatization in healthcare arises primarily from practitioners' negative views of illicit drug use, and (2) practitioners' negative attitudes toward people who are HCV positive is the result of their lack of awareness and/or information about HCV. The authors critiqued this body of research as limited in its applications to anti-stigma interventions because they do not acknowledge the institutional and structural forces within the healthcare system that can result in discriminatory practices, despite practitioners' attitudes and knowledge. Other authors (Rhodes et al., 2004; Srivastava & Francis, 2006) have suggested that the focus on blaming individual practitioners for discriminatory behaviour distracts institutions from attending to the structural stigmatization that is embedded in everyday institutional healthcare practices.

Although the individual level is important to consider in the development of anti-stigma interventions, interventions that remain focused on the individualistic psychological explanations of stigmatization are insufficient to tackle the complex issue of stigmatization (Heijnders & Van Der Meij, 2006). Recently, there has been a call for research that examines factors beyond individual practitioners that explains in part why and how stigmatization of the population occurs within healthcare and informs interventions to mitigate these factors (Parker & Aggleton, 2003; Paterson et al., 2007; Weiss & Ramakrishna, 2006; Weiss, Ramakrishna, & Somma, 2006).

Method

The research had an interpretive description design (Thorne, Con, McGuinness, McPherson, & Harris, 2004) that seeks to describe the phenomenon of interest in order to capture the inherent complexity of the experience (Thorne, 2008). This is accomplished by seeking the complex interactions and themes of the general experiences of the topic of interest, without losing sight of the individual experiences that contribute to the more generalized findings (Thorne, 2008). The method uses an inductive approach that encourages researchers to take the knowledge gained from their studies and apply it to the practice setting (Thorne, 2008).

Accordingly, the analytic framework for the research is developed by critically analysing relevant work and identifying salient attributes and components of the phenomenon under study. Such a framework provides a beginning point upon which decisions are made about research design. For example, as the geographical location of the hospital may influence access to specialists who can be called upon for advice in particularly challenging positions with this population, we interviewed service providers in both urban and rural areas of Nova Scotia, Canada in regions within the province with the greatest incidence of people who use illicit drugs and are HCV positive (Brenckmann, 2003).

Analytic framework

In accordance with interpretive description, the analytic framework for the research is derived from relevant literature and the researchers' experience with the hospital care experience of people who use illicit drugs and are HCV positive (Thorne et al., 2004). The analytic framework for the research (see Fig. 1) included consideration of the structural components of hospitals as institutions, as well as particular hospital departments, as impacting the way in