

Review paper

The depiction of stigmatization in research about hepatitis C

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Abstract

In the past decade, there has been an increasing emphasis by researchers regarding the stigmatization of people who are hepatitis C positive as they seek health care. Because the vast majority of people with hepatitis C have a history of injection drug use, they are frequently assumed by practitioners to be injection drug users (IDUs), blamed for acquiring the disease, and viewed as irresponsible, immoral, and unworthy. Such stigmatization may cause people who have hepatitis C to avoid testing, treatment and care, as well as to not disclose their hepatitis C or injection drug use to practitioners. The purpose of this paper is to critically examine the representation of stigmatization in 21 published research reports from 1995 to 2006, with a specific focus on how these depictions have shaped the current understanding of interventions to address stigmatization of people with hepatitis C by health care practitioners. We will identify two themes in this literature: (1) hepatitis C-related stigmatization in health care settings arises primarily from practitioners' negative views of injection drug use, and (2) practitioners' negative attitudes toward people with hepatitis C are the result of their lack of awareness and/or information about the disease and/or about injection drug use. We will illustrate that similar themes have informed anti-stigma initiatives in other diseases, notably HIV/AIDS and mental illness, which have had little sustained effect in changing practitioners' behaviour toward the stigmatized population. In conclusion, we will call for research that considers factors beyond the individual practitioner as contributing to the stigmatization of people with hepatitis C, such as social, structural and institutional forces that shape practitioners' interactions with people with hepatitis C in health care settings.

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Contents

Hepatitis C-related stigmatization research	365
Stigmatization as arising from injection drug use	365
Stigmatization arising from lack of knowledge and/or awareness	369
Insights from HIV/AIDS and mental health	370
Discussion	371
Conclusion	372
References	372

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The experience of stigmatization has been identified by researchers as one of the most significant issues facing people who are hepatitis C positive (Hopwood & Southgate, 2003; Zacks et al., 2006). Stigmatization of people who are hepatitis C positive within health care is a concern not only because of its pervasiveness across all health care disciplines (Glacken,

Kernohan, & Coates, 2001; Treloar, Hopwood, & Loveday, 2002), but because practitioners have the power to make decisions that directly impact those who are ill and those decisions may compromise the well-being of the person seeking care (Corrigan, 2004).

The reports of widespread discrimination against people who are hepatitis C positive situate the stigmatization of people with hepatitis C in health care settings, primarily hospitals (Hopwood & Southgate, 2003). In one research study (Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003), 57 percent of the 257 respondents who were hepatitis C positive reported that they had been stigmatized by health care workers. In another study involving only injection drug users (IDUs) with hepatitis C, more than 90 percent of the respondents indicated they had experienced discrimination enacted by health care staff (Habib & Adorjany, 2003).

The stigmatization of hepatitis C within health care is widely acknowledged to stem from its association with injection drug use (Fontana & Kronfol, 2004; Hopwood, Treloar, & Bryant, 2006; Remis, 2002). Because the majority of people with hepatitis C have a history of injection drug use (Fontana & Kronfol, 2004), they are frequently assumed by health care practitioners to be IDUs, blamed for acquiring the disease, and viewed as irresponsible and unworthy (Hopwood et al., 2006). Research has revealed that health care workers commonly describe IDUs as among the most unpopular of patients (McLaughlin, McKenna, & Leslie, 2000) and expect them to be more dangerous, more manipulative, less grateful, less co-operative, less pleasant, more aggressive, less truthful, and more demanding than patients with most other profiles (Link & Phelan, 2006).

As the conceptualization and investigation of stigmatization in this field of study will significantly shape the future development of interventions to reduce hepatitis C-related stigma, it is timely to review how this body of research has contributed to our understanding of stigmatization, to challenge some of the assumptions and insights that are derived from this research, and to suggest ways in which researchers could more effectively address this issue in the future. In this article, we will critically examine the representation of hepatitis C-related stigmatization in 21 research reports published from 1997 to 2006, with a specific focus on how these depictions have shaped the current understanding of interventions to address the stigmatization of people with hepatitis C within health care settings. We will propose that this body of research has assumed a highly individualistic perspective that blames health care practitioners for their attitudes and provides an incomplete foundation for the development of anti-stigma interventions in the future. We will draw on insights derived from the two fields that have dominated in the development and evaluation of anti-stigma interventions in health care and are similar to hepatitis C in regard to the prevalence and impact of stigmatization (Zickmund, Hillis, Barnett, Ippolito, & LaBrecque, 2004), namely mental illness and HIV/AIDS, to identify future directions regarding anti-stigma interventions.

We acknowledge that researchers vary considerably as to their definition of stigmatization, ranging from a personal attribute that marks the person as being flawed and deviant (Goffman, 1963) to notions of stigmatization as a process of social exclusion (Reidpath, Chan, Gifford, & Allotey, 2005). We define stigmatization as incorporating five interrelated components: the identification and labelling of difference; stereotyping; distinguishing members of the stigmatized group as “them” in contrast to the non-stigmatized group as “us”; and the exercise of power (Link & Phelan, 2006).

Hepatitis C-related stigmatization research

The 21 published research reports (see Table 1) represented in the following review are either investigations in which hepatitis C-related stigma and discrimination was a sole focus or studies of the general experience of living with hepatitis C in which stigma was a significant finding. This research arises primarily from Australia, a nation that has a well-established framework for the handling of hepatitis C-related stigmatization and discrimination (Crofts, Louie, & Loff, 1997).

Only one study focused on practitioners’ knowledge of the disease and their attitudes (van de Mortel, 2002). The remaining research relied on retrospective accounts of stigmatization experienced by people with hepatitis C. Stigmatization that is specific to health care settings was a significant but not the sole focus of most studies; however, a significant portion of the discussion of the findings in the published reports of the research are devoted to hepatitis C-related stigma in health care settings.

Most of the research included in this review used questionnaires or structured interviews to capture self-reports of people with hepatitis C about their experiences and/or perception of stigmatization. Little detail was provided about the derivation of the stigma scales used in this research or their validity and reliability. The limitations of such stigma scales have been identified as centring on memories and beliefs, not actual events and behaviours, and focusing on the individual, not the context that supports or constrains stigmatization (van Brake, 2003).

Two themes are evident in the body of research: (1) hepatitis C-related stigmatization in health care settings arises primarily from practitioners’ negative views of injection drug use, and (2) practitioners’ negative attitudes toward people with hepatitis C are the result of their lack of awareness and/or information about the disease and/or about injection drug use.

Stigmatization as arising from injection drug use

All researchers represented in this review refer to stigmatization as arising from the association of hepatitis C with injection drug use. It is widely recognized that stigmatiza-

Table 1
Overview of research reports included in review

Author(s)	Sample	Research Design	Findings
Banwell et al. (2005)	40 lesbian, 66 bisexual, and 449 heterosexual women with hepatitis C	Questionnaire developed after consultation with panel of experts, including people with hepatitis C	Lesbian (63 percent) and bisexual (57 percent) women more likely than heterosexual women (44 percent) to report discriminatory practices by health care practitioners
Butt et al. (in press)	33 individuals with Hepatitis C who were outpatients in three hepatology clinics or members of an IDU advocacy group	Think-aloud tape recording of experiences in living with hepatitis C for 1 week; initial and two interviews related to think-aloud	Stigma of IDUs who are hepatitis C positive is greater than that related to injection drug use or hepatitis C alone All participants experienced stigma by health care practitioners Participants believed they received a lesser quality of care and had to wait longer than other patients in emergency departments if they were current IDUs
Crockett and Gifford (2004)	25 Australian women between the ages of 18 and 43 years, who were current or past injecting drug users and who had been diagnosed with HCV	Individual interviews One focus group interview with health workers who provide treatment and care to this population	A number of key issues were identified that women believed impacted negatively on their lived experiences of HCV. Of most concern was the meaning of HCV and the social stigma attached. Stigma coupled with the lack of knowledge and awareness among health professionals and the high cost of treatment contributed to women's reluctance to seek support and care 46 percent of reported discrimination occurred in health care settings. Only 11 percent of the 37 incidents were reported to an authority
Crofts et al. (1997)	37 reports of hepatitis C-related stigma provided by people with hepatitis C to support groups, councils or organizations in Australia	Content analysis of reports	46 percent of reported discrimination occurred in health care settings. Only 11 percent of the 37 incidents were reported to an authority
Day et al. (2004)	606 participants with hepatitis C over the age of 15	Face-to-face structured interview about discrimination in health care	40 percent experienced hepatitis C-related discrimination within last 2 years. Current IDUs more likely to report discrimination than past IDUs or those who had never injected. Those who recently consulted a GP or specialist were more likely to report discrimination than those who had not consulted a physician and women were more likely than men to report discrimination
Day et al. (2003)	237 heroin users who were hepatitis C positive	Structured interview regarding experience of discrimination and whether they thought it was related to hepatitis C, IDU or both	Discrimination was reported by 22 percent of the 237 IDUs who reported being HCV-positive Sixty-seven incidents of stigmatization were reported, of which half were perceived to be due to their drug user status, 15 percent of these incidents were due to HCV status and 25 percent due to a combination of both. Twenty-five incidents occurred in a health care setting; 13 resulted in the service being withheld
Dunne and Quayle (2002)	32 women who had acquired hepatitis C through prophylactic treatment for RH hemolytic disease	Focus groups	Organizational aspects of the health care system resulted in the diagnosis being exposed to others and a lack of confidentiality. This was viewed by participants as stigmatization

Table 1 (Continued)

Author(s)	Sample	Research Design	Findings
Faye and Irurita (2003)	24 people with hepatitis C + 6 others (spouse, nurse, persons working in field of addiction)	Grounded theory study using multiple interviews	Participants felt condemned by diagnosis. They experienced and anticipated stigma. Stigma related to either fear of transmission or illicit drug use. All experienced stigma regardless of mode of infection Only 50 percent satisfied with current medical care
Gifford, O'Brien, Bammer, Banwell, and Stoove (2003)	462 women with hepatitis C 17 percent had never injected illicit drugs; 47 percent current IDUs (within past 12 months)	40 min questionnaire and SF-12; return rate of 75 percent Mailed survey	Women who had never injected more likely to receive referral to specialist Almost half (48 percent) reported discrimination on basis of hepatitis C, not IDU Those who were current IDUs more likely to be dissatisfied or very dissatisfied with care Forty percent of men reported that they believed they received less favourable treatment from health care professionals than those without hepatitis C
Gifford et al. (2005)	312 men who reported having hepatitis C; lived in Victoria, Australia	Self-administered questionnaire regarding health status, symptomology, satisfaction with medical care, consultation and diagnosis process. Included SF-12	Forty percent of men reported that they believed they received less favourable treatment from health care professionals than those without hepatitis C
Grundy and Beeching (2004)	8 women with hepatitis C in England	Single interviews re experience of living with hepatitis C	Stigma a significant issue for all but one. Believed that health care practitioners often categorized and labelled them negatively
Habib and Adorjany (2003)	271 IDUs with hepatitis C	Self-administered questionnaire	65 percent indicated stigmatization in health settings related to being an IDU Females more likely than males to indicate stigmatization was due to hepatitis C status alone Current drug users more likely than other respondents to indicate they had received no information about their diagnosis from the physician
Hopwood and Treolar (2004)	504 people living in NSW with self-reported HCV infection	58-item questionnaire	Discrimination most common in health care settings and among the young, those who knew others with the disease, and those who reported hepatitis C-related fatigue
Hopwood et al. (2006)	504 people living in NSW with self-reported HCV infection	Questionnaire (see Hopwood & Treolar, 2004)	Stigma fourth highest concern for respondents
Minuk, Gutkin, Wong, and Kaita (2005)	185 patients in a hepatology out-patient clinic who had hepatitis C. Seventy newly diagnosed	Structured interview	Experiences of stigmatization more common among women and in those with higher depression scores
Schaefer, Scheurlen, Felten, and Kraus (2005)	103 hospital outpatients with hepatitis C	Structured interview	Attitudes of health care practitioners key in determining the participants' response to their illness. Women more sensitive to negative judgments of others; men defended themselves against these
Temple-Smith et al. (2004)	20 women and 12 men with hepatitis C in Australia	Single interview	Participants experienced difficulty in challenging inappropriate and discriminatory infection control practices by health care practitioners Infection control was perceived as a tool to express disapproval about participants' lifestyle choices and social group membership
Treolar and Hopwood (2004)	19 people who were hepatitis C positive	Semi-structured interviews	

Table 1 (Continued)

Author(s)	Sample	Research Design	Findings
van de Mortel (2002)	160 nurses	Questionnaire	The majority of nurses reported non-discriminatory attitudes towards patients with hepatitis C Nurses' level of experience, perceptions of personal risk of contracting hepatitis C in the workplace, and recent incidents of sharps injuries correlated with willingness to care for these patients
Zickmund et al. (2003)	257 patients with hepatitis C attending a liver clinic in Iowa	Semi-structured interview and a demographic profile, as well as sickness impact scale and hospital anxiety depression scale	147 patients (57 percent) reported hepatitis C-related stigmatization. Women reported stigmatization more than men. Age, education, professional status, and mode of transmission did not influence likelihood of stigmatization. Outcomes of stigmatization included anxiety, depression, decreased quality of life, loss of control, and difficulty coping
Zickmund et al. (2004)	322 outpatients diagnosed with chronic HCV infection and treated at a tertiary referral hospital's hepatology clinic	Patients were asked to provide demographic information and to complete a semi-structured interview, the sickness impact profile (SIP) and hospital anxiety depression (HAD) scale	A total of 131 (41 percent) study patients reported communication difficulties with physicians including physicians' poor communication skills, physician incompetence regarding hepatitis C, being misdiagnosed, misled, or abandoned, or being stigmatized by their physician

tion of IDUs is pervasive in health care settings (Banwell, Bammer, Gifford, & O'Brien, 2005); however, people with hepatitis C who have never been an IDU frequently report that they have received inadequate and judgmental health care from hospital staff because practitioners assume that they received the virus from sharing needles as they injected illicit drugs (Dunne, 2001; Gifford et al., 2005).

We located only one study (Day, Ross, & Dolan, 2003) that purported to investigate whether hepatitis C-related stigmatization is related solely to injection drug use, to hepatitis C alone, or to a combination of hepatitis C and injection drug use. The 237 heroin users in the study were asked the reason they experienced stigmatization. The options they were given were injection drug use, hepatitis C, and both injection drug use and hepatitis C. Half of the reported instances of stigma were perceived by the respondents to be due to their drug user status, 15 percent of these incidents were believed to be due to their hepatitis C status and 25 percent were thought to be due to both hepatitis C and injection drug use; however, the researchers offered no other options to explain the stigmatization, such as homelessness. Nor did they ask the respondents to generate other possible explanations for this phenomenon.

Although most researchers sampled people with hepatitis C who acquired the virus from a variety of sources, the few studies that include only IDUs (Crockett & Gifford, 2004; Habib & Adorjany, 2003) have determined that there may be differences in the experience of people who are IDUs in comparison with those who acquired the virus from "innocent means", such as blood transfusions.

Current IDUs with hepatitis C appear to be particularly at risk for stigmatization by health care practitioners (Hopwood & Southgate, 2003; Treloar et al., 2002). They report significantly more experiences of discrimination (Day, Jayasuriya, & Stone, 2004) and receiving a lesser quality of care than those who are not current IDUs (Treloar et al., 2002). One study found that current IDUs were more likely to report that they had received no explanation from their physicians about their diagnosis than those who were past IDUs (Hopwood & Treloar, 2004). Another discovered that current IDUs were likely to report less satisfaction with their medical care than former IDUs or people who had never injected drugs (Gifford et al., 2005). Some researchers (e.g., Zickmund et al., 2004) have found no correlation between mode of acquisition of the virus and reports of patient–physician conflict; however, they did not specifically inquire about illicit drug use and instead asked respondents to indicate the probable mode of acquisition of the virus.

Many researchers acknowledge that hepatitis C-related stigma is multifaceted; it may be confounded and exacerbated by other attributes that are assigned negative labels, such as illicit drug use, poverty, ethnicity, homelessness, and prostitution. Few, however, investigated how the stigmatization of people who are hepatitis C positive differs among those with various attributes. One study indicated that lesbian and bisexual women, particularly IDUs, are more likely

that heterosexual women with hepatitis C to report negative treatment by health care practitioners (Banwell et al., 2005). There is limited evidence to suggest that hepatitis C-related stigmatization may be gender-based (Crockett & Gifford, 2004; Temple-Smith, Gifford, & Stooze, 2004). Women with hepatitis C have been found to report greater sensitivity to stigmatization, but men with hepatitis C were determined to defend themselves against stigma (Crockett & Gifford, 2004; Temple-Smith et al., 2004).

Stigmatization arising from lack of knowledge and/or awareness

The majority of relevant research has entailed interviews or surveys of people with hepatitis C about the incidence and impact of stigmatization. One research study involving practitioners surveyed them regarding their knowledge of the disease and their attitudes toward patients with hepatitis C (van de Mortel, 2002). Despite this lack of focus on the perspectives of practitioners, the discussions by researchers of the research findings typically centre on the need for health care practitioners to have more education and/or awareness about hepatitis C and injection drug use. For example, one group of authors (Day et al., 2004) writes that health care practitioners require training in dealing with IDUs. Crofts et al. (1997) suggest that there is a dire need for "education of medical and other health care providers about the modes of transmission and risks [of hepatitis C] in different settings" (p. 638). While education about addiction and hepatitis C is undoubtedly useful in assisting health care practitioners to understand how to treat IDUs with hepatitis C, it is not a guarantee that the recipients of such education will integrate this knowledge in their clinical practice.

Blaming health care practitioners for hepatitis C-related stigmatization does not acknowledge other factors, beyond the attitudes of the individual practitioner, that precipitate and sustain stigmatization of this population. A possible explanation for stigmatization of IDUs with hepatitis C lies in the cycle of mistrust, anger and lack of cooperation that is perpetuated when people who have had negative experiences within the health care system in the past anticipate similar experiences in encounters with patients or with health care practitioners. This phenomenon has been well documented in chronic illness. For example, Paterson (2001) indicates that practitioners who have had experience with people with diabetes who do not comply with their prescribed regime may respond to all people with diabetes as if they are untrustworthy. If patients perceive they have been treated in a disrespectful and dismissive way, they may respond in a self-defensive manner by withholding significant information from the practitioner and refusing to adhere to the regime that the practitioner prescribes. This, in turn, perpetuates the stereotype that the practitioner maintains. Likewise, health care practitioners who have had experiences with some IDUs with hepatitis C who leave the hospital earlier than advisable,

fail to show up for appointments, or not follow the prescribed regime may anticipate similar behaviour on the part of any patient who is known to be an IDU with hepatitis C. This may result in the practitioner denying the patient needed resources or services (Edlin et al., 2005).

A limitation of the assumption that strategies to foster practitioners' enhanced knowledge and awareness will eliminate stigmatization of people with hepatitis C is that stigmatization can occur in health care settings despite the positive attitudes and knowledge base of health care practitioners. There are institutional and structural forces within the health care system that can result in discriminatory practices, despite health care practitioners' positive attitudes toward people with hepatitis C (Butt, Paterson, & McGuinness, *in press*; Treolar & Hopwood, 2004).

Stigmatization exists when people with particular diseases are viewed as being unworthy of social investment (Reidpath et al., 2005). There are many forces within health care that contribute to practitioners' defining IDUs with hepatitis C as meriting less investment than others. For example, one marker of deservedness of social investment is the person's ability and willingness to engage in reciprocal exchange (Reidpath et al., 2005). In traditional health care, practitioners expect patients to provide accurate and relevant information about their health status, to cooperate in the treatment and management of the person's care, and to accord the practitioner respect and authority. This is viewed as the basis of a trusting practitioner–patient relationship; therefore, an IDU with hepatitis C who is a poor historian, leaves the hospital against advice, or responds to the authoritarian manner of the practitioner in an aggressive manner may be viewed as contravening these social norms and being less deserving of investment than other patients.

Stephenson (2001) suggests that sources of hepatitis C-related stigmatization include institutional and departmental policies about who is eligible for treatment, who receives treatment and the types of support are available to this population within a hospital. One research team has proposed that the on-site presence of a physician who is an addiction specialist and ready access to appropriate mental health services are structural components to reduce the incidence of stigmatization of IDUs who are hepatitis C positive in hospital Emergency rooms (Hoskins, Salmon, Binks, Moody, & Benger, 2005). Other researchers demonstrated that the administrator's willingness to fund care and treatment for IDUs was a significant determinant in what services practitioners were able to provide to this population (Astone, Strauss, Hagan, & Des Jarlais, 2004).

Structural stigmatization is implied but not clearly described in the majority of research about hepatitis C-related stigma in health care settings. For example, in one study involving interviews of people with hepatitis C, researchers reported that practitioners tied their judgments about appropriate infection control to their assessments of the risks presented by the person with hepatitis C (Treolar & Hopwood, 2004). The researchers did not specifically

explore how the infection control policies within the health care setting may have contributed to the practitioners' decision making. Butt et al. (*in press*) quote IDUs in their study as saying that hospital departments vary as to their acceptance and respect of people with hepatitis C. This is congruent with the findings of researchers who demonstrate that institutional cultures that normalize stigmatization may create social pressure for the health care staff to stigmatize particular patient populations (Wright, Linde, Rau, Gayman, & Viggiano, 2003).

Insights from HIV/AIDS and mental health

There is a need for research about the occurrence and experience of hepatitis C-related stigma in health care to be “framed in ways that will ultimately feed into and nurture the development of advocacy and intervention aimed at reducing levels of stigmatization” (Parker & Aggleton, 2003, p. 21). This depends to large degree on our willingness to challenge the underlying assumptions that have characterized the field of study to date, as well as to incorporate the insights that scholars in fields such as HIV/AIDS and mental illness that have considerably longer experience have generated in their critique of anti-stigma interventions.

The first generation of research about stigmatization in mental illness and HIV/AIDS shares a similar profile to research in the field of hepatitis C; i.e., it is largely descriptive about the experiences or perspectives of the stigmatized (Brown, Macintyre, & Trujillo, 2003). Anti-stigma interventions have been derived from this research. Although there have been a few interventions designed to enhance the ability of the stigmatized to cope with stigma (Abel, Rew, Gortner, & Delville, 2004), most anti-stigma interventions are intended to increase the tolerance of the stigmatizers to the stigmatized population.

In both HIV/AIDS and mental illness, anti-stigma interventions have been largely based on cognitive-behavioral and social-cognitive models that emphasize education and contact as critical to reducing stigmatizing behaviour (Parker & Aggleton, 2003; Valimaki, Suominen, & Peate, 1998). Such anti-stigma interventions are underpinned by a view that people who stigmatize others will want to and are able to behave differently if they have the necessary knowledge and/or awareness about the disease and about the harmful effects of stigmatization (Reidpath et al., 2005). They are often based on a moralistic view that presupposes that if practitioners know the harm they cause by their stigmatization, they will change their attitudes toward the population to be more accepting and positive (Corrigan, 2004). These foundational beliefs, however, have been recently challenged by research that has tested the outcomes of such interventions. For example, Brown et al. (2003) determined that the majority of the studies they reviewed in HIV/AIDS demonstrated small to moderate positive effects of education or contact interventions, several also found negative and mixed effects

(Brown et al., 2003). A similar profile of anti-stigma interventions exists in the field of mental illness; i.e., they demonstrate limited or no effect (Corrigan, 2004).

A major criticism of anti-stigma interventions has been the assumption that practitioners' knowledge is correlated with their attitudes toward the stigmatized population in health care settings (Valimaki et al., 1998). Research cited by Reidpath et al. (2005) demonstrates that medical students' knowledge of HIV was "completely uncorrelated with the high level of stigmatizing attitudes" (p. 471) toward those who are HIV positive. In addition, most anti-stigma interventions in HIV/AIDS and mental illness have been based on descriptive research that has entailed retrospective accounts by those who are stigmatized. These are removed from the actual experience and are decontextualized (Corrigan, Markowitz, & Watson, 2004).

Many authors point to the conceptualization of stigmatization in HIV/AIDS and mental illness as the reason why anti-stigma interventions in these fields have been largely ineffective in reducing stigmatization (Lee, Chiu, ATsang, Chiu, & Kleinman, 2006; Rhodes, Singer, Bourgois, Friedman, & Strathdee, 2004). The individualistic focus in most anti-stigma interventions has been criticized as culturally irrelevant to many ethnic and racial populations (Parker & Aggleton, 2003). In addition, blaming the individual practitioner for discriminatory behaviour often functions as a substitute for sustained organizational attention to the stigmatization that is embedded in everyday institutional practices in health care, such as methods of referral, wait times, and staffing (Srivastava & Francis, 2006).

Discussion

A review of research pertaining to hepatitis C-related stigma to date has revealed that it has significant limitations (e.g., it is not clear if the stigma associated with injection drug use is part or the whole of hepatitis C-related stigma; it does not differentiate the experience of stigmatization among those who are hepatitis C positive and have various attributes common to other stigmatized groups, such as the homeless or poor). It is also apparent that it mirrors the first generation of stigma research in the fields of mental illness and HIV/AIDS; i.e., it conceptualizes stigma as individualistic and decontextualized from the political, economic and social contexts in which it occurs. In HIV/AIDS and mental illness, such research led to anti-stigma interventions that focused on education and contact as the remedy for health care practitioners' stigmatization of those with the illness. Education and contact anti-stigma interventions are underpinned by a view that people who stigmatize others want to and are able to behave differently (Reidpath et al., 2005). They have been demonstrated to have limited success in changing people's behaviour in the long term, largely because the view that knowledge and contact will positively influence people's behaviour ignores the social and structural forces that play

a significant role in driving such stigmatization (Parker & Aggleton, 2003; Rhodes et al., 2004).

Recent authors are calling for reforms in the conceptualization of stigma as the basis of the development of anti-stigma interventions; they emphasize the need to move beyond the individualistic psychological models of stigmatization that have dominated the field of study to date (Parker & Aggleton, 2003; Weiss & Ramakrishna, 2006; Weiss, Ramakrishna, & Somma, 2006). They have indicated the need to reframe stigmatization as playing a significant role in producing and reproducing social relations of power and control. Such conceptualizations require researchers to reflect about why people with hepatitis C are socially excluded beyond individual practitioners' negative attitudes and to consider what forces create and sustain stigmatization in different contexts.

Reidpath et al. (2005) propose that one reason why research about stigmatization has provided a poor foundation for anti-stigma interventions is that it has been based on the assumption that stigmatization can best be understood as focusing on the micro perspective (i.e., interaction between two individuals); researchers have largely neglected the macro (i.e., societal, cultural, political, historical, and contextual) perspective. There is no denying that the individual level is important to consider in the development of anti-stigma interventions but interventions at this level are not sufficient to tackle the complex issue of hepatitis C stigmatization (Heijnders & Van Der Meij, 2006).

If we are to develop evidence-based anti-stigma interventions that portray stigmatization as beyond a matter of individual attitudes and incorporating wider socio-cultural and other contexts, we must be prepared to entertain innovative and perhaps new theoretical frameworks and research designs. It will require us to move beyond trying to change the individual practitioner to fostering social transformation and community mobilization (Heijnders & Van Der Meij, 2006; Parker & Aggleton, 2003). As well, it will require us to incorporate the perspectives and experiences of the people who are affected by the disease in the development of interventions that are effective at the intrapersonal level (Heijnders & Van Der Meij, 2006) and at broader institutional, community and social levels. For example, a hospital could form a council consisting of paid members who were people with the disease and users of the hospital services. This council could inform and provide feedback about intervention development to ameliorate stigmatization of people with hepatitis C within the institution. Likewise, researchers who wished to design or evaluate anti-stigma interventions could form advisory committees composed of people with hepatitis C to participate as co-researchers in the project. Such a partnership would contribute significantly to anti-stigma interventions that reflect the real-life experience of people with the disease and significantly impact the incidence of stigmatization in health care settings.

As Weiss and Ramakrishna (2006) indicate, stigmatization of people with a disease cannot be effectively addressed

by a single approach. Although it is important to address the misperceptions and lack of understanding regarding hepatitis C that are held by individual stigmatizers, there is also a need for approaches that will negate the impact of stigmatization on the one who is stigmatized, as well as a need for interventions that will address how access to and the provision of equitable and non-judgmental care is impeded by governmental and institutional policies and structures, such as financing of health care.

Conclusion

In this article, we have reviewed the research to date about stigmatization of people with hepatitis C in health care settings. We have suggested that the understanding of the origins and enactment of stigmatization must be understood beyond an issue of an individual practitioner's blame. We acknowledge in Brown et al. (2003) words that the "ubiquity of stigma and its persistence—makes it an extremely important yet difficult area of research" (p. 67). Despite this, we call for researchers to develop new and creative approaches to the study of stigmatization as intersecting culture, power and difference (Parker & Aggleton, 2003) in health care. We concede, however, that although the focus of this manuscript has been stigmatization within health care, there is a need for research that examines the forces that foster and sustain stigmatization of people with hepatitis C in other institutions, such as the justice and educational systems.

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