
Living With the Stigma of Hepatitis C

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Stigma poses significant challenges to those with chronic hepatitis C (CHC), their social networks, communities, and society. This study's purpose was to identify and describe how people lived with CHC and made self-care decisions. Data are presented from interviews and daily recordings of 26 study participants. Experiences of stigma were attributed primarily to misconceptions about the cause and transmission of the disease and its association with illicit drug use. Perceptions and responses to stigma were context-dependent, flexible, and varied over time. Stigma created barriers to access of health services and undermined the social supports required to address self-care needs and illness management. The extent and severity of stigma suggests that interventions to reduce or eliminate stigma will require individual, structural, and systemic changes. Further study is required to clarify the relationship between the trajectory of CHC and the experience and responses to stigma.

Keywords: *stigma; hepatitis C; chronic; illicit drugs; HIV*

Stigma is an important attribute of the experience of living with chronic diseases, particularly when it is associated with the possible transmission of the disease to vulnerable people (Sandelowski, Lambe, & Barroso, 2004). The negative impact of stigma on the health of people with chronic

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conditions, such as HIV, is well-established (Fife & Wright, 2000; Fontana & Kronfol, 2004; Taylor, Costello, Alt, Yates, & Tashima, 2002). The stigma associated with chronic hepatitis C (CHC) has recently emerged as a research focus. In his seminal work, Goffman (1963) conceptualized stigma as an attribute that discredits an individual in the eyes of society and results in the person being devalued, discriminated against, and labeled as deviant. He proposes that stigma negatively affects the self-image of those to whom the negative attribute is ascribed and that stigma poses considerable challenge in interactions with those who are deemed as normal (i.e., those perceived as not having that attribute; Schultze & Angermeyer, 2003).

Description of Stigma and CHC

An estimated 130 million to 170 million people worldwide are chronically infected with the hepatitis C virus (Armstrong, 2003; Poynard, Yuen, Ratziu, & Lai, 2003; Remis, 2004). In the developed world, the predominant modes of transmission (60% to 75%) are associated with injection drug use (IDU) and shared drug equipment (Chou, Clark, & Helfand, 2004; Remis, 2004; Zou, Tepper, & El Saadany, 2000). Because the majority of people with CHC have a history of illicit drug use (Patrick, Buxton, Bigham, & Mathias, 2000; Remis, 2004; Zou, Tepper, & Giulivi, 2000), people diagnosed with CHC are blamed for acquiring the disease and placing others at risk (Herek, Capitano, & Widaman, 2003). The resultant stigma associates people who have CHC with criminality, promiscuity, untrustworthiness, noncompliance, and HIV/AIDS (Crandall, 1991; Glacken, Kernohan, & Coates, 2001; Sastre, Bacq, Mullet, & Sorum, 2002; Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003). The strength of the stigma arising from the association with illicit drug use is so pervasive that those who contract the virus through so-called "innocent" means (e.g., contaminated blood products) often experience stigmatization regardless of the source of their infection (Anti-Discrimination Board of New South Wales, 2001; Hopwood & Treloar, 2003; Zickmund et al., 2003).

Individuals with CHC report perceiving and experiencing indirect, as well as direct, stigma. Indirect stigma, or the expectation of stigma that can occur regardless of actual experience (Sandelowski et al., 2004), can negatively affect health (Pinel, 2002). For example, a significant number of people report diminished self-esteem on being diagnosed with hepatitis C (Waller, 2004; Zickmund et al., 2003) possibly because CHC infection is deemed as "dirty" and "immoral" within most developed countries (Zickmund et al., 2003), and

people with the disease internalize these social views (Sandelowski et al., 2004). Consequently, some people with CHC expect others to have negative opinions of them, and they believe that these opinions are justifiable (Joachim & Acorn, 2000).

Direct or enacted stigma in relation to CHC occurs in a variety of settings, including government agencies, the private sector, family and friendship networks, and health care centers (Anti-Discrimination Board of New South Wales, 2001; Armishaw & Davis, 2002; Hopwood & Treloar, 2003). Health care settings are a major source of stigma, particularly among those with a history of illicit drug use (Aitken, Kerger, & Crofts, 2002; Anti-Discrimination Board of New South Wales, 2001; Dunne & Quayle, 2002; Glacken et al., 2001; Hajela, 1998; Hopwood & Treloar, 2003; Sladden, Hickey, Dunn, & Beard, 1998; Zickmund et al., 2003). The stigma associated with CHC leads some people with the disease to experience disregard for personal well-being, shame, feelings of uncleanliness, lowered self-esteem, demoralization, social isolation, loss of income, decreased quality of life (Mason, Carlisle, Watkins, & Whitehead, 2001; Zickmund et al., 2003), and declines in health (Dunne & Quayle, 2002; Weiss & Ramakrishna, 2001). Ultimately, the fear of stigmatization may cause those at risk of CHC to avoid being tested and those who have CHC to avoid treatment and care (Herek & Capitanio, 1993; Herek et al., 2003).

Stigma is socially constructed and varies according to history and context. As a consequence, researchers have recently argued that the research agenda for stigma must include the documentation of the burden of stigma for specific diseases in varying contexts to investigate the social causes and factors that fuel stigma (Keusch, Wilentz, & Kleinman, 2006). Our knowledge of stigma and CHC is limited by the paucity of studies examining this issue. Experiences of CHC stigma described in studies are based on retrospective accounts that limit the exploration of the complexities and variations in individual experience and responses over time. Most studies rely on structured interviews or questionnaires to measure the location, frequency, and intensity of stigma. Lacking are qualitative, in-depth narrative accounts needed to map the foundations of stigma toward CHC and develop a framework for intervention research.

Stigmatization of people with CHC is a complex social phenomenon involving individual and societal judgments. The published findings on stigma and CHC indicate that there are multiple sources both individual and societal, that experiences occur in diverse settings, and that the impact includes negative health outcomes and reduced quality of life. Qualitative

studies are needed to understand the stigma experiences of those with CHC in context, their responses, and whether the experiences and responses change in time.

Purpose

The purpose of the research study was to identify and describe how people with CHC lived with their disease and made everyday self-care decisions. This article presents one component of this study: the experience of stigma.

Method

Design

An interpretive descriptive method was used to explore the day-to-day experiences, perceptions, and responses of individuals living with CHC (Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, Kirkham, & O'Flynn-Magee, 2004). Experiences were explored by employing a modified think-aloud (MTA) technique refined by Paterson and colleagues (Paterson, 2001; Paterson, Russell, & Thorne, 2001; Paterson & Thorne, 2000).

Sample

The number of participants required to capture variations in experience was determined in previous studies using a similar research design (Paterson & Thorne, 2000; Paterson, Thorne, & Russell, 2002). Criteria for inclusion in the study included residency in British Columbia, age of 18 or older, diagnosis of CHC, ability to speak and understand English, absence of known cognitive or memory-deficit significant enough to negatively affect the ability to participate in the study, and no need of home nursing or institutional care. Following ethical approval obtained from the University of British Columbia's University Behavioural Ethics Review Committee, recruitment was facilitated by the staff at two hepatology clinics and an advocacy center. A written and verbal description of the research was provided to potential participants. Those who were interested telephoned the coordinator to obtain further information, confirm their eligibility, and, if applicable, arrange consent and an interview.

Because the focus of the research was not specifically stigma and much of the data pertained to events that were occurring at the time of the research, not all participants reported experiences or perceptions of stigma. Twenty-six of 33 participants described experiences of and/or perceptions of stigma. We are unable to identify demographic or other (e.g., social support network) factors that differentiated those who reported stigma and those who did not. The demographic particulars of the sample are represented in Table 1. Half the sample was male and half, female. The majority of participants did not complete high school, lived with the disease for at least a decade, and identified illicit drug use as the source of their infection. Twelve participants stated that they were illicit drugs users at the time of the study. Three participants had received treatment for CHC but were unsuccessful in eradicating the virus. The remainder had been declared ineligible for antiviral therapy because of current illicit drug or alcohol use ($n = 20$) or had refused it ($n = 3$).

Procedure

Data were obtained during a 2-week period using a brief demographic questionnaire, audiotaped interviews, and modified think-aloud recordings. All audiotaped data were transcribed verbatim. A brief demographic questionnaire and an open-ended intake interview were used to collect demographic information and descriptions of a typical day, health problems, and illness beliefs related to CHC and self-care. In keeping with exploratory methods, the concept of stigma was not introduced through questioning but rather allowed to emerge during the interview (Prior, Wood, Lewis, & Pill, 2003).

Following the interview, participants were assigned a 1-week period for daily tape recording of their experiences, thoughts, and actions in regard to living with CHC, in keeping with an MTA technique refined by Paterson and colleagues (Paterson, 2001; Paterson et al., 2001; Paterson & Thorne, 2000). The MTA technique provides data consisting of brief narrative statements on the components of the decision-making process and their sequence, the precipitating situation or incident, outcomes of the decision, and the contextual factors that affect the decision making. Two think-aloud telephone interviews were included, one at the midpoint and one at the end of the weeklong recording period. The MTA tape was recovered prior to the interviews on Day 4 and 8 to note the salient themes and statements for further exploration. For example, if a participant stated in the MTA, "I met my friend for lunch and we discussed my

Table 1
Demographics of Sample

Characteristic	Participants Interviewed (<i>N</i> = 26)	
	Number	Percentage
Gender		
Female	13	50%
Male	13	50%
Ethnicity		
Euro Caucasian	23	88%
Aboriginal	3	12%
Source of infection		
Illicit drug use	16	61%
Blood transfusion	6	23%
Needle-stick or work exposure	2	8%
Unknown	2	8%
Education		
Did not complete high school	14	54%
High school diploma	6	23%
Postsecondary	6	23%
	Mean	Range
Age (years)	47	33 to 76
Time since infection (years)	10.4	1 to 39

Note: Time since infection and source of infection are based on self-report.

vitamin C deficiency. That is my code name for hepatitis C.” The interviewer would restate this sentence and then ask questions such as, “Tell me more about why you use a code name for hepatitis C. How has using a code name helped you with your self-care?” Interview questions were also generated from themes that arose in data of other interviews (e.g., some participants indicated that they avoided certain events or situations because they caused a great deal of stress; therefore, we explored with others whether there were certain activities or events that seemed to produce greater changes in their stress level than others). Participants were also asked to clarify contradictions between their MTA tapes and interviews (e.g., “You said in your first interview that you never drink alcohol, but when you went to lunch with your boss, you had wine. Why?”).

Data Analysis

Analysis of the data concurrent with the data collection enabled us to develop questions for further exploration and clarification during follow-up interviews (Thorne et al., 1997). The first step of the analysis was to read and reread the transcripts to identify and code the concepts that were inherent in the participants' experience as they reported it. A concept is a word, phrase, or sentence that provides a unit of information about the decision-making process—specifically, the context, initial and overall actions, and the desired goals and consequences (French et al., 1996). Transcripts were reviewed and coded by trained members of the research team. Members reviewed each other's coding and discussed any discrepancies to arrive at consensus. The concepts were identified and classified according to the nature of the theme (e.g., anticipated stress, stigma). Management of the data was facilitated by the computer software program NVivo. The concept of stigma emerged from the data and was clustered in two thematic areas: the experiences and perceptions of stigma and the responses to stigma. In a final step, to complete the analysis and gain consensus on the meaning of stigma and CHC, the research team reanalyzed the data by reviewing the transcripts, coding, and meeting notes using the individual and consensus protocols established from this and previous work. Stigma was only one of several themes identified in the data; other themes are described elsewhere (Paterson, Butt, McGuinness, & Moffat, 2006).

Findings

In accordance with the findings of previous research about stigma in CHC, the stigma that the participants experienced and/or perceived arose primarily from misconceptions about the cause and transmission of the disease as well as its association with illicit drug use (Anti-Discrimination Board of New South Wales, 2001; Fontana & Kronfol, 2004; Tompkins, Wright, & Jones, 2005). Participants described the stigma of CHC as unique from that attributed to illicit drug use alone. They indicated that they experienced and/or perceived stigma regardless of how they had contacted the disease. In their descriptions of their responses to stigma, participants revealed that stigma was not necessarily damaging to their self-esteem and that their responses to stigma changed over time and in different contexts.

Stigma of CHC

The participants' experiences of stigma included cases involving another person who threatened, berated, dismissed, or negatively judged them on the basis of their having CHC. They indicated that most often, the other person responded to them in this way because of ignorance or misconceptions about CHC or because the person associated CHC with illicit drug use. When the interviewer asked participants who were illicit drug users (IDUs) how the stigma of CHC was the same or different from that of illicit drug use, they emphasized that the stigma of people with CHC is different "because not only are you a druggie and all that this implies, but [it is assumed because you have CHC] you don't care about other people because you shared needles." One participant stated that he "wasn't well-liked" by health care practitioners when they thought he was "just a user," but when he developed CHC, they treated him "like I was a lower lowlife than before."

The most common report of stigma was the withdrawal of care, support, or services by health care practitioners. Sometimes this involved other people leaving the room or refusing to care for the person with CHC. One man who disclosed to his physician that he was an IDU with CHC recounted being subjected to judgmental statements and being asked not to return. In other situations, the withdrawal of care was more subtle. For example, one participant indicated that a nurse recoiled and "took a step back" when she recognized that the participant had CHC and was at the clinic to have his blood tested. In another situation, a participant compared an acupuncturist's manner before and following her disclosure of CHC.

You know, like he'd been so nice to me before, giving me free acupuncture. You know, he was just so amazing and then that time, the change was just—I mean, I sickened him. And it's not that I did. He was afraid of the disease just like I was (before diagnosis). And for obviously probably the same reasons, lack of awareness and knowledge and education, but you know, he must have felt that he could get it to some degree.

Another common account of stigma was when other people, including coworkers, neighbors, and family members, restricted the participant's access to events, places, and people. One participant observed that her grandmother had said, "Well, you could come and visit, but where are you going to go to the washroom?" One woman told of how her neighbors would not allow their children to play with her children because they feared she might transmit CHC to them. Another participant stated, "My best

friend, she doesn't let her children pick their food, my food, off their plate anymore." Even if the other person did not specify the reason for the restriction, participants typically assumed it was because of the CHC. For example, a participant described how she was not permitted to touch small children and concluded it was because "they were afraid that kids would be liable to catch the hep C from me." Most participants recognized these situations as arising from unfounded fear based on a lack of knowledge about the disease and how it is transmitted.

Participants recounted another example of stigma as when others, particularly family members, cautioned the person to keep the CHC a secret.

I think, well, I know my oldest son didn't want to sort of accept it. Because he was with me one day at the health food store— and I was talking to the manager, something about hep C or something, and then he went out. And when I came out, he said, "Mom, why do you talk about hepatitis, hep C? Why do you do that?"

Perception of Stigma

At times, although they had not actually experienced stigma, participants perceived stigma when they compared the services they were receiving with those provided to people who did not have CHC; they concluded that they were not receiving a similar quality of service. For example, a participant who went to the hospital with a fractured leg observed others in the Emergency Department with similar fractures who received more attention, analgesia, and support than he did. He concluded that because he was an IDU who had CHC that he was insignificant: "You're not important. You're just, you know, in the back of the bus."

Many participants spoke of an implicit and highly discrediting profile of people with CHC that exists within society. They described society's general view of people with CHC as IDUs who are irresponsible and untrustworthy. A nurse admitted that previous to her own diagnosis with CHC, she had made similar assumptions about people whom she suspected of having CHC. Participants held out little hope that the societal profile would change. "It's never going to be a popular disease . . . it's always going to be acquainted with the poor and the dirty and the downtrodden."

Some participants viewed the public-health materials and health-promotion campaigns directed at eliminating CHC as evidence of the stigma of CHC. One participant complained that the informational pamphlets about CHC

emphasize illicit drug use and imply that an IDU with CHC is irresponsible, dangerous, and engages in risky behaviors without regard for the well-being of others. Another participant proposed that the emphasis on harm reduction in CHC suggests that the transmission of CHC is the responsibility of the person with CHC and “if someone else gets it, it’s because you didn’t do your part.”

Although participants framed the majority of statements as individual responses to stigma, a few participants emphasized the role of the media and public health in eliminating the stigma of CHC. They called for “more positive stories” of CHC in the media and the need to address some of the societal issues that result in CHC (e.g., poverty, addiction) rather than to “simply blame us for getting the disease and then passing it on.” Some participants said that they felt strongly that an important and necessary response to stigma is engaging a prominent person as a role model and spokesperson for CHC; that is, if a prominent person disclosed that he or she became infected through needle sharing, then the experience of hepatitis C would become normalized and stigma would become less of a force in their lives.

Participants who had received the virus from tainted blood or who did not know the initial source of their infection concurred with statements of other participants about the stigma of CHC, saying, “They automatically think you’re an addict—an addict who shares needles.” They described health care practitioners who “searched my arms to see if I had needle marks” even after they had indicated they did not and had not used illicit drugs. They stated that they often tried to disassociate themselves from those who were infected through illicit drug use by introducing themselves as an “innocent victim” and by emphasizing that they were different from those “who knowingly put themselves at risk.” They agreed, however, that the stigma of CHC is so resilient that it affects everyone regardless of the source of infection. “It’s so stigmatized that it’s hard to feel that even myself will ever be accepted as having hep C from innocent means.”

Responses to Stigma

The participants’ responses to stigma varied; some responses were consistent within a given context, whereas others changed in time. The responses included those directed inward, such as self blame, or directed outward toward individuals or groups. The responses were personal, emotion-focused (intrinsic), and/or problem-focused (extrinsic). Emotional responses included hurt feelings, shame, embarrassment, low self-worth, fear, anger, depression, isolation, surprise, concern for others, and feeling overwhelmed

by the additional burden of stigma when dealing with a chronic illness. Problem-solving responses included covering, concealing information, educating others, blaming self and/or others, deflecting blame, and changing relationships.

For some participants, the response to stigma changed in time and was framed beyond the individuals involved and a specific event to one based on cumulative experiences. As one participant explained, after a while he learned to view stigma as a positive opportunity for introspection and learning and change: "It's taken some years to get here. But can I learn from this...that's been how I feel, almost glad that it happened, because it's opened up a lot for me, about life." Another participant explained that although initially she blamed herself, in time she thought that the responsibility for the illness should be shared with society,

where the feeling to blame might be a result of your own inabilities to deal with the reality and the depth of the truth or just how our society confers things on us that society finds difficult to accept responsibility for.

Emotional Response

Embarrassment, combined with a decision to conceal the CHC to protect loved ones from ridicule and shame, was a common response to stigma: "I'm quite embarrassed about my condition. So, ah, plus my kids. They're really, ah, I didn't want my kids, ah, being exposed to ridicule." Embarrassment occurred most often when the participant was in the presence of someone whose respect he or she valued. In situations when they were not concerned about others' opinion of them, participants were more likely to "shrug it off" or "just ignore it."

Self-blame was a response to stigma noted by 10 participants. One participant infected through illicit drug use explained that "it's my fault." A health service provider infected through a needle-stick injury described self-blame in response to the perceptions of her coworkers that the injury was because of her personal carelessness.

Problem-Solving Response

All participants described ways that they had developed to deal with the stigmatization of CHC. The most common of these was concealment of the diagnosis. Many participants spoke of "covering" or maintaining an identity to the outside world as a person without CHC. "I don't openly

advertise my condition.” They talked about “paying a price” for this when they were symptomatic or on treatment as to maintain a façade of normalcy, they were required to continue working no matter how they felt. Some described only providing enough information to partially explain manifestations of the disease such as fatigue or hair loss by making comments such as, “I’m on chemo” or “I have a liver problem, and it just can’t process alcohol the way yours does.” Others indicated that they chose “who to tell and who not to” on the basis of what they predicted the repercussions would be if they disclosed their diagnosis. Often this required “testing the waters” by interjecting comments about CHC or other blood-borne diseases, such as HIV, to determine how the person responded. “I told a story at lunch about someone being fired because he had AIDS, and I waited to see what they would say.” If the response to their “testing” was positive, participants were more likely to disclose their diagnosis of CHC.

Concealment of CHC sometimes led to changes in lifestyle and social withdrawal. One person explained that to conceal the diagnosis and symptoms, such as fatigue, he quit his job and withdrew socially during a 5-year period. This decision caused him to worry about being able to earn a living again and provide for his children: “I’ve gone from very, very busy, to ah, absolutely nothing.” He stated that he “suffered from bouts of depression” about the cumulative losses.

Participants who experienced stigma after disclosing CHC responded in a variety of ways. Some disclosed their illness to everyone; they interpreted this as being proactive and eliminating the need for others to gossip or speculate about their illness. Alternatively, some participants were selective in who they told in an effort to control unwanted disclosure by others and the possible negative consequences such as “telling someone like your boss, who can have you fired.” Others explained that they avoided situations that would necessitate disclosure of their CHC, such as joining CHC advocacy groups or visiting health care providers. One participant explained that she “didn’t take a manicurist course” because she felt she “would have to disclose.” For others, negative experiences in disclosing their CHC had a compounding effect, increasing their reluctance to disclose or increasing their use of selective disclosure.

Some participants viewed stigma associated with CHC as a challenge and took actions to extinguish it by educating others. “I mean, I had to teach people about the disease. They didn’t really know the difference, even my own health care workers. My coworkers didn’t know the differences between hep B and C.” One participant, a health care professional, viewed

stigma experiences as her opportunity to act as a role model and demonstrate that having CHC “does not make you less of a person.”

Rejecting Stigma

A few participants talked about refusing to blame themselves for their disease. One participant described rejecting self-blame, saying, “So I don’t really get too worked up. I really believe that it’s not something I need to be embarrassed, ashamed of.” Four participants who were IDUs at the time of the study stated that they no longer “paid attention” to stigma because “survival is where it’s at for me right now.” Some participants described struggling to alter their responses by reframing their self-image to be more positive. Three participants described how their association with a CHC support group helped them to develop strategies to negate the stigma and to bolster their self-esteem. Four others discussed how affirmation from others, such as their friend, physician, or alternative therapist, helped them to develop the confidence to reject the stigma of CHC.

Discussion

The research findings bear many similarities to those of research in the field of HIV-related stigma. Similarly to the research in HIV, the findings of this study point to the “pervasiveness and the profoundly distressing nature” (Gray, 2004, p. 51) of CHC-related stigma. As in HIV, the stigma associated with CHC is based on cultural fears of contagion and negative social views of people who engage in risky behaviors (e.g., IDUs) and are members of devalued social groups, such as the unemployed (Gray, 2004; Green, 1995). Those who are infected with CHC are viewed as dangerous and irresponsible, blamed for contacting the virus and expected to transmit the virus without regard for the safety of others (Sandelowski et al., 2004). The findings of this research study point to the fluid, flexible, and contextual nature of responses to stigma in CHC that are similar to those reported in HIV. These findings suggest that how someone may respond to stigma when newly diagnosed may change in time as they encounter additional experiences with stigma or as they develop more awareness about stigma as they live with the disease. Alonzo and Reynolds (1995) proposed that among people with HIV, there may be a stigma trajectory that explains people’s responses to stigma in various phases of their disease experience. Such a trajectory has not been empirically investigated in CHC.

Some important differences exist between the findings of stigma-related research in HIV and those of the current study. In contrast with research in the field of HIV, participants in this study did not necessarily experience diminished self-esteem because of stigma. The majority of research about the stigma of HIV has indicated that stigma often has negative effects on the ill person's self-esteem, particularly if the individual internalizes the stigma (Gray, 2004). Many participants in the current study rejected the stigma of CHC as invalid, particularly as they lived with the disease and came to see that viewing themselves as less than worthy because they had CHC was neither useful nor accurate. Still other participants responded to the stigma by countering the attitudes of others with education and advocacy. It is possible that stigma may have actually enhanced, not decreased, their self-esteem because it was the trigger to challenge the negative attitudes of others.

One way of interpreting the finding that some participants did not experience decreased self-esteem in response to stigma is to consider the changes that some people with chronic illness make as they live with the disease. Paterson, Thorne, Crawford, and Tarko (1999) illustrated that some people with diabetes are able to transcend the threats to self that are part of living with the disease, such as stigma, because they differentiate the self from their illness and their diseased body over time. For example, some people in their research viewed the responses of others to them as a challenge and an opportunity rather than as a threat to their self-esteem. These researchers represent such transcendence as a strategy to mediate the negative impact of the illness and to maintain self-integrity. They suggest that it is a process of evolution in living with a chronic disease that can be impeded or advanced by others, such as health care practitioners. Further research is needed to determine the personal and contextual factors that foster such an evolution in people with CHC.

Some researchers have proposed that people with CHC experience diminished self-esteem because of the stigma of the disease (Waller, 2004; Zickmund et al., 2003). Recent evidence from the field of mental health suggests that lowered self-esteem is not an inevitable consequence of stigma (Camp, Finlay, & Lyons, 2002). The findings of the current study confirm that diminished self-esteem is not inevitable and the effects of stigma can change in time. Future research directed at how the experience of stigma impacts the self-esteem of people with CHC through time would help elucidate which factors, such as employment status and disease progression, influence these effects.

The majority of research about stigma in chronic diseases has concentrated on individuals' experiences or perceptions of stigma that occur in personal interactions. This research highlights the need for further study about how structural and systemic influences can be sources of stigma and how people with CHC experience these. For example, participants noted that negative images in the media, the judgmental discourse of people with CHC in public-health information, as well as inequities in health and social services, were cited as deeply hurtful and discriminating. This gives credence to Link and Phelan's (2001) conceptualization of stigma that is positioned within the context of social, economic, and political power. Researchers should draw on theoretical orientations and methodologies, such as institutional ethnography, that depend on a critical consciousness about the political, historical, socio-cultural, and economic construction of stigma of CHC in such research (Link & Phelan, 2001).

The research findings have important implications for clinical practice and the impact of stigma on the burden of disease. The traditional focus of health care professionals exclusively on the virus and its impact on the body should be expanded to include the effects of stigma. A recent study by Minuk, Gutkin, Wong, and Kaita (2005) confirmed that patients with CHC have concerns that reach beyond the biological impact of the virus, such as social stigma and lifestyle change; these topics were not covered during visits to a tertiary-care referral center. Clinicians can help to reduce the additional burden of disease that stigma creates by recognizing the effects of stigma and discussing the experience with their patients.

One of the participants' responses to perceived stigma in CHC was the way in which they disclosed or chose not to disclose the source of their infection. Many, including nurses who had been infected through needle-stick injuries, framed their source of infection so that it would be more culturally acceptable. When health care practitioners demand that people with CHC disclose the source of infection, particularly before they have developed a rapport with the person, they may cause the person to experience fear, embarrassment, and shame. This leads to important considerations for health care practitioners' interactions with people who are infected with hepatitis C. Health care practitioners should be sensitive to the possible outcomes of such behavior, including that the infected person may avoid further care, leading to possible progression of the disease.

Conclusion

Stigma poses significant challenges to those with CHC, their social networks, their communities, and society. This study provides valuable insights into the extent and severity of stigma through the perspective of those chronically infected. It also challenges commonly held assumptions about the stigmatization of CHC, such as that it is inevitable and leads to diminished self-esteem. The study was not designed specifically to capture the experience of stigma in CHC and, consequently, participants who took stigma for granted as part of their everyday experience may not have discussed it or discussed it in a comprehensive way. Despite this limitation, the research has provided evidence of stigma as a significant element of living with CHC. It points in a dramatic way to the need for more studies that examine stigma in living with CHC so as to capture individual variation in experience and response over time. The findings suggest that interventions to reduce or eliminate stigma will require individual, structural, and systemic changes.

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