

Stigma in the context of hepatitis C: concept analysis

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Abstract

Title. Stigma in the context of hepatitis C: concept analysis.

Aim. This paper is a report of a concept analysis of stigma in the context of hepatitis C.

Background. Stigma is a complex and powerful social phenomenon that influences the course of illness and marginalizes populations. Knowledge of hepatitis C stigma is central to assisting people with hepatitis C self-manage their illness and reduce the disease burden.

Data sources. Thirty studies from 1995 to 2007 located in health and social sciences databases constituted the data for an evolutionary concept analysis and ecological theory guide the review.

Findings. Stigma is a subjective and variable, perceived and/or experienced phenomenon, most frequently but not exclusively viewed as negative, that has inter-related intrapersonal, interpersonal and structural or institutional dimensions. The antecedents of hepatitis C stigma are help-seeking situations most frequently occurring in healthcare settings. Attributes include the association of hepatitis C with illicit drug use, fear of transmission of a contagious and life-threatening infection, acceptable level of risk, and the power to impose restrictions on the part of healthcare practitioners, family and friendship networks and society. Stigma consequences are mainly, but not exclusively, negative.

Conclusion. A central and distinctive feature of hepatitis C stigma in the Western world is its association with illicit drug use. Further research is required to understand the complexities associated with the sociocultural, situational and structural features that influence the stigma experience as well as the trajectory of the disease to understand the concept better and inform nursing practice.

Keywords: evolutionary concept analysis, hepatitis C, human immunodeficiency virus, illicit drug use, nursing, stigma

Introduction

Stigma is an important facet of the social impact of many chronic diseases (Weiss *et al.* 2006). Different diseases and contexts evoke similar as well as distinctive features of stigma. The powerful impact of stigma associated with chronic infectious diseases such as leprosy, tuberculosis and

more recently human immunodeficiency virus (HIV) leads to avoidance of healthcare services, negative effects on personal health and reduced effectiveness of public health programmes in controlling disease transmission (Jaramillo 1998, Herek *et al.* 2003). Thus, stigma constitutes a substantial burden of illness, requiring those offering healthcare services to recognize and mitigate its effects (Link & Phelan 2006).

Research spawned by the epidemic of the hepatitis C virus (HCV), a relatively new and usually chronic infectious disease affecting 170 million people worldwide, which translates to 1–2% of the population of Western countries (Remis 2004, World Health Organization 2006), identifies stigma as one of the most important issues facing those infected (Hopwood & Southgate 2003, Zacks *et al.* 2006). Nurses in public health and clinical practice are the main service providers for the prevention and management of HCV. Hence, they must be aware of, and sensitive to, the conditions that precipitate and perpetuate stigma (Wagner *et al.* 1996). In this paper I aim to analyse HCV stigma using an evolutionary framework for concept analysis and applied ecological theory (Stokols 1996, Rodgers 2000).

Background

Hepatitis C and the populations vulnerable to infection

Hepatitis C virus was first identified in 1989 through laboratory tests. It is not preventable by vaccines and is primarily spread through blood-to-blood contact with an infected person. The sharing of needles and equipment associated with illicit drug use accounts for 60–75% of infections in the developed world (Chou *et al.* 2004, Remis 2004). Illicit drug users (IDU) are most vulnerable to infection, with an estimated 50–95% of IDUs having HCV (Memon & Memon 2002). Other transmission routes include blood or blood products used prior to the implementation of improved screening techniques in 1990, needlestick injuries, tattooing and other types of body piercing (Shepard *et al.* 2005). About 75% of those infected with HCV experience a chronic form of the disease and about 25% of these people experience progressive liver disease resulting in cirrhosis, end-stage liver disease and/or liver cancer and premature death (Seeff & Hoofnagle 2002). Although new antiviral therapies can arrest viral replication for some, only a small proportion of individuals attempt therapy (Falck-Ytter *et al.* 2002). Consequently, the majority of people infected with HCV experience the effects of the disease for decades and probably for life (Lee *et al.* 2006).

Stigma of hepatitis C in the context of infectious diseases

There is a long history of social exclusion and negative health effects associated with the stigma of infectious diseases such as leprosy, tuberculosis and, more recently, HIV (Alonzo & Reynolds 1995, Kelly 1999, Cross 2006). The impact of infectious disease-based stigma can be accentuated, as populations vulnerable to disease may already experience stigma

because of other personal attributes such as race, age, poverty or sexual preference (Parker & Aggleton 2003). Stigma can impede the success of disease control measures when people avoid or delay diagnosis and treatment, leading to continuing risk of disease transmission (Jaramillo 1998, Nicholls *et al.* 2003).

Infectious diseases have shared as well as distinctive features of stigma. Shared stigma experiences of people with HIV and HCV include: 1) fear of transmission of the disease (Grundy & Beeching 2004, Sandelowski *et al.* 2004); 2) blame for acquiring their disease through irresponsible or inappropriate behaviour (Albrecht *et al.* 1982, Habib & Adorjany 2003); and 3) being subjected to inappropriate use of precautions and/or infection control procedures, e.g. physicians and nurses withhold or increase the difficulty of accessing services (Day *et al.* 2003, Treloar & Hopwood 2004). What makes stigma distinctive is the expression of widely different emotions and perceptions (Dijker & Koomen 2006). Stigma is therefore a complex phenomenon, the experience of which differs by illness and the social circumstances of those affected (Fife & Wright 2000).

Researchers have recently argued that stigma research must include documentation of the burden of stigma for specific diseases in varying contexts to allow better investigation of the social causes and factors that fuel stigma (Keusch *et al.* 2006). Examining stigma in the context of a specific disease such as HCV facilitates understanding of which stigmatization dynamics are generic and which are a function of the contextual characteristics of the disease. In analyzing stigma, the disease-based context is critical, as nursing interventions are often tailored to specific diseases. Without a disease-specific focus, the complexity of nursing work with people with chronic diseases such as HCV is contradicted (Duncan *et al.* 2007).

Evolutionary concept analysis

Consistent with the view that HCV stigma is uniquely derived from its context, Rodgers (2000) method of evolutionary concept analysis was chosen to examine HCV stigma research. This method is based on a systems view of interconnectedness in the world and the philosophical approaches of Toulmin (1972) and Wittgenstein (1953/1968). Rodgers (2000) emphasis on the context-specific and changing nature of concepts is well-suited to the emerging field of HCV research, where the concept of HCV stigma is only recently being employed and where its characterization may change as it is further explored. This method requires a rigorous, systematic and transparent approach to sample selection and data collection and the use of qualitative

research methods for data analysis to increase validity. For example, an inductive approach to data analysis and explanation of the interpretation and meanings ascribed to the data clearly shows the writer's logic. This type of analysis yields a consensus about the concept that can be used to inform nursing practice, knowledge development and research (Rodgers 2000, Timmins 2006).

Ecological theory, a multi-level, multi-system framework that attempts to explain the relationships that shape an individual's development, has been drawn on to inform a comprehensive search strategy, to interrogate and organize the data from several levels (individual or intrapersonal, interpersonal, and organizational/structural) and to explore patterns of interrelationships (Bronfenbrenner 1977, 1979, Belsky 1980). Ecological theory has subsequently been adapted and applied to understand complex healthcare issues, especially those that affect vulnerable populations and lead to health disparities (Whittemore *et al.* 2004, Reifsnider *et al.* 2005). Although it is a general theory, rather than a nursing-specific theory, it was selected for its utility in nursing for enhancing understanding of complex health issues that go beyond the individual, for example, the various levels of influence such as families, healthcare providers, healthcare institutions can be uncovered without losing sight of the individual (Laustsen 2006).

Data sources

The first step in applying Rodgers (2000) method is to identify the concept for review and its setting, in this case, the concept of stigma as it is portrayed within context of HCV. The second step involves the identification and selection of an appropriate data sample through a literature search. The present search involved computerized searches of multiple databases, including Medline, CINAHL, PsycINFO, EM-BASE, the Cochrane Database of Systematic Reviews and Google (for unindexed literature). Combinations of the subject heading 'hepatitis C AND stigma' with its related or surrogate terms were used, e.g. hepatitis C and stigma or discrimination or prejudice. Subject headings were exploded to include all possible subheadings. Keywords such as patient experience, quality of life and qualitative research were searched in combination with hepatitis C, as stigma often emerges as an important research finding in qualitative research. Reference lists from papers retrieved were hand searched for additional publications. Based on knowledge from previous work, the search was limited to the time-period in which the entire body of HCV stigma research was projected to be found, 1995–2007. To be included, papers had to be in English and peer reviewed primary HCV

research or systematic reviews. Government research reports and classic works, those most frequently cited references that contributed to the emergence of the concept of stigma associated with hepatitis C, were added for the historical review. Sources that included explicit as well as implicit definitions of stigma were included to gain as much information as possible on how the concept is currently characterized and explained.

The remaining steps of the method comprise data retrieval, management and analysis. Samples chosen were retrieved and subjected to a process of inductive thematic analysis (Thorne 2000, Charmaz 2002). To operationalize the method, each paper was read several times to identify relevant themes and position them within the categories of Rodgers (2000) framework, i.e. historical context, attributes, antecedents, consequences, references, surrogate terms and exemplar. The schema included coding by author/s, date of publication, primary concept, discipline (first author), country (first author), and citation type. The data were entered into NVIVO 7 software to facilitate data interrogation, refine the coding structure and thematic relationships. Notes were kept to record thoughts, interpretations, questions and decisions about the data and its interpretation. Surrogate terms were recorded but not subjected to further analysis.

Findings

A total of 1227 abstracts were reviewed and 30 studies were selected as a sample in which stigma was the primary research question or a significant element (see Table 1). This sampling procedure met Rodgers (2000) baseline criteria of a minimum sample of 30 studies. However, the total number of papers that met the criteria was too small to choose a percentage of the studies at random, as recommended by Rodgers. The sample, mainly from Australia, appears to comprise all the English language HCV stigma research.

Nine studies contained an explicit definition of stigma. All research was cross-sectional. Methods included surveys, structured or semi-structured interviews and one exploratory study using semi-structured interviews and a modified think-aloud technique to explore experiences and perceptions in context (Butt *et al.* 2008). The percentage of those with HCV reporting stigma varied across studies, indicating that it may not be universally experienced. No researchers attempted to validate the accuracy of the data through observation or other confirmatory methods. Discrimination was the most frequently employed surrogate term.

The sample was not critiqued with respect to research design or methods, as the focus was to identify the factors associated with the concept of HCV stigma. However, it is

worth noting that most studies focused on the individual viewpoint, primarily for those with HCV, and only three focused on the knowledge and attitudes of practitioners (van de Mortel 2002, 2003, Temple-Smith *et al.* 2006). In the sample, the organizational or structural aspects of stigma were identified mainly as societal views, while other influences such as culture or healthcare institutional policies were largely unaddressed.

Historical and theoretical context of the concept of HCV stigma

No consensus emerged from the literature on what constitutes a definition of stigma or a stigma theoretical framework. In its early use the term stigma was used to indicate a mark or brand attached to individuals. The term carries a positive meaning when used in the context of religious rituals such as self-flagellation, or a negative connotation when used to refer to the branding of slaves or prisoners to indicate their inferior status (Herek 2002). The current dictionary definition 'a symbolic mark of disgrace' (Pearsall 1999) is consistent with the historical roots of stigma as a negative personal attribute.

There is consensus in the literature that stigma research was catalysed by Goffman's (1963) seminal theory portraying stigma from a deviance perspective, i.e. as a negative personal attribute or trait that discredits the individual in the eyes of society. Subsequent research in psychology and the social sciences on the nature, sources and consequences of stigma has extended Goffman's theory from discipline-specific theoretical perspectives, resulting in a wide variation in how it is defined and conceptualized. There is agreement that stigma is a social process that is shaped by contextual factors (Weiss *et al.* 2006) such as power and domination, in combination with existing inequalities of race, class, gender and sexuality (Parker & Aggleton 2003).

Theories in social psychology focus on the social aspects of stigma as psychological variables at the individual level, e.g. the relationship between stigma and self-esteem, with identity-threat theory the foremost perspective (Major & O'Brien 2005). Social psychology theories are thus centred on the characteristics of stigma that encroach on the individual such that the individual becomes the primary agent (those stigmatized are viewed as passive victims rather than active agents) in whom stigma processes occur (Oyserman & Swim 2001, Yang *et al.* 2007).

Sociological models focus on the social aspects of stigma, with an emphasis on extension beyond the individual to the social sphere where meaning is generated through social interaction. For example, Link and Phelan (2001) theorize

that society creates boundaries through labelling, stereotyping, separating 'them' the out-group from 'us' the in-group and invoking power over those in the out-group. Interestingly, as with social psychology, sociological models locate the effects of stigma within the individual (i.e. the stigmatizer or stigma recipient). More recent conceptualizations have begun to expand the sphere of stigma to include forms of social control, i.e. structural or institutional features, that arise from political, economic and historical sources (Parker & Aggleton 2003, Corrigan *et al.* 2004).

Link and Phelan (2001) suggest that definitions of stigma vary with the circumstances in which it is studied as well as the disciplinary and theoretical backgrounds of the researchers. They argue that variation is acceptable as long as stigma is clearly defined within the particular circumstance in which the term is used. From the literature reviewed, stigma can be defined as a complex social phenomenon that is shaped by personal, interpersonal, and structural processes such as institutional policies and their interrelationships in specific contexts.

Attributes of HCV stigma

Attributes are the key or recurrent characteristics of the concept found in the literature (Rodgers 2000). The present data analysis, summarized in Table 2, revealed that HCV stigma attributes are subjective and variable, perceived and/or experienced with interrelated intrapersonal, interpersonal and structural or institutional dimensions. The intrapersonal or individual dimension may be experienced through internalization and acceptance of society's views. For example, the internalization of oneself as an infectious agent may lead to self-descriptions as being 'dirty' and 'diseased':

I've got something that's not okay, I've got something that might repulse people...I've got something that people might potentially...decide they want to not be friends with me. I've got something that's oh – a diseased state, a disability. (Conrad *et al.* 2006, p. 127)

The interpersonal dimension is experienced in encounters with others or perceived through interpretations of situations. Finally, stigma as an institutional or structural dimension is perceived or experienced from messages in educational materials or in institutional policies and procedures, such as restrictions on eligibility for antiviral therapy or excessive infection control procedures.

A striking and recurrent structural (disease-based) attribute is the association of HCV with IDU. This pervasive and persistent feature is so enveloping that those infected through other means, such as needlestick injuries that occur in the provision of healthcare, experience stigma by association: 'It's

Table 1 Summary of hepatitis C virus (HCV) stigma research

Reference Region	Database	Discipline	Sample	Definition of stigma?	Method
Banwell <i>et al.</i> (2005) Australia/New Zealand (NZ)	CINAHL	Health Sciences	Subset of Gifford <i>et al.</i> 2003 (#5) 462 self-reported hepatitis C (HCV) positive women: 40 lesbian, 66 bisexual and 343 heterosexual women	No	Questionnaire
Conrad <i>et al.</i> (2006) Australia/NZ	CINAHL	Health Sciences	77 patients of tertiary referral centres and community members not seeking care for HCV	No	Semi-structured interview
Crockett and Gifford (2004) Australia/NZ	CINAHL	Health Sciences	July 1999 to April 2000 25 women, current/past injection drug user (IDU), self-reporting as HCV positive and 'small group' of health workers	Yes	Semi-structured interview and one focus group with health workers
Crofts <i>et al.</i> (1997) Australia/NZ	Medline	Health Sciences	37 case history reports collected from self-reported HCV positive individuals	No	Questionnaire (content analysis of information collected)
Day <i>et al.</i> (2003) Australia/NZ	Medline	Multi-disciplinary	237 mostly heroin users self-reported as HCV positive	Yes	Questionnaire & structured interview for those reporting HCV discrimination
Day <i>et al.</i> (2004) Australia/NZ	CINAHL	Multi-disciplinary	606 self-reported HCV positive persons	No	Semi-structured interview
Faye and Iruita (2003) Australia/NZ	CINAHL	Nursing	24 current or past IDU persons self-reporting as HCV positive and 6 others (spouse, nurse, substance abuse workers)	Yes	Semi-structured interview
Fraser and Treloar (2006) Australia/NZ	CINAHL	Social Sciences	Six current or past HCV positive participants drawn from larger study, including non-IDU	Yes	Semi-structured interview
Gifford <i>et al.</i> (2003) Australia/NZ	Medline	Health Sciences	462 women self-reported as HCV positive	No	Self-administered questionnaire
Gifford <i>et al.</i> (2005) Australia/NZ	Medline	Health Sciences	308 men with self-reported HCV diagnosis	No	Questionnaire
Habib and Adorjany (2003) Australia/NZ	CINAHL	Social Sciences	271 current or past IDUs in Australia (65% HCV positive) January–June '98 52% male, 46% female and 2% transgender	No	Self-administered questionnaire
Harris (2005), Australia/NZ	Google	Social Sciences	20 self-reported HCV positive persons	No	Interview (no details)

Table 1 (Continued)

Reference Region	Database	Discipline	Sample	Definition of stigma?	Method
Hepworth and Krug (1999) Australia/NZ	CINAHL	Medicine	Six self-reported HCV positive persons	Yes	Interview (no details)
Hopwood and Treloar (2004) Australia/NZ	Medline	Social Sciences	504 self-reported HCV positive persons	No	Questionnaire
Hopwood <i>et al.</i> (2006), Australia/NZ	PsychINFO	Social Sciences	504 self-reported HCV positive persons	Yes	Self-administered questionnaire
Temple-Smith <i>et al.</i> (2006) Australia/NZ	Medline	Health Sciences	25 Australian dentists	Yes	Semi-structured interview
Temple-Smith <i>et al.</i> (2004) Australia/NZ	CINAHL	Health Sciences	32 self-reported HCV positive persons, most current or past IDU	No	Semi-structured interview
Treloar and Hopwood (2004) Australia/NZ	CINAHL	Social Sciences	19 self-reported HCV positive people	No	Semi-structured interview
van de Mortel (2002), Australia/NZ	CINAHL	Nursing	58 healthcare workers (doctors, registered nurses, ward persons and physiotherapists)	No	Self-administered questionnaire
van de Mortel (2003) Australia/NZ	CINAHL	Nursing	160 Australian nurses from random sample	No	Self-administered questionnaire
Dunne and Quayle (2002) Europe	PsychINFO	Social Sciences	32 self-reported HCV positive women	No	Structured focus group
Golden <i>et al.</i> (2005) Europe	CINAHL	Social Sciences	90 persons with confirmed HCV diagnosis	No	Structured interview for Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)
Golden <i>et al.</i> (2006) Europe	CINAHL	Social Sciences	87 persons with confirmed HCV diagnosis (subset of above study)	Yes	Axis I Disorders and Questionnaire Structured interview for DSM-IV Axis I Disorders and Questionnaire
Grundy and Beeching (2004) Europe	CINAHL	Nursing	Eight HCV positive women with record of diagnosis (1 cleared virus)	No	Semi-structured interview
Schäfer <i>et al.</i> (2005) Europe	CINAHL	Medicine	103 persons with HCV confirmed by presence of antibodies and circulating HCV Ribonucleic Acid (RNA)	No	Questionnaire
Butt <i>et al.</i> (2008) Canada/US		Nursing	33 self-reported HCV positive persons	No	Interview and modified think-aloud technique

Table 1 (Continued)

Reference Region	Database	Discipline	Sample	Definition of stigma?	Method
Mimuk <i>et al.</i> (2005) Canada/USA	Medline	Medicine	185 HCV positive persons with confirmed record of HCV diagnosis	No	Structured interview
Zacks <i>et al.</i> (2006) Canada/USA	Medline	Medicine	175 HCV positive persons confirmed by detectable HCV antibody report	No	Questionnaire
Zickmund <i>et al.</i> (2003) Canada/USA	Medline	Medicine	257 persons chronically infected with HCV	Yes	Semi-structured interview and Questionnaire
Zickmund <i>et al.</i> (2004) Canada/USA	Medline	Medicine	322 persons with confirmed HCV diagnosis	No	Structured interview and Questionnaire

so stigmatized that it's hard to feel that even myself will ever be accepted as having hep. C from innocent means'. (Butt *et al.* 2008, p. 213)

The attributes of a contagious and life-threatening infection are striking features of HCV that are frequently used to explain rejection of, or limitation on, the behaviours of people with HCV. Two attributes related to the contagious nature of HCV are fear of transmission and acceptable level of risk. Rejection of those with HCV because of fear of transmission is presumed by those with HCV to be directly related to a lack of knowledge by healthcare practitioners, families and friendship networks. However, acceptable level of risk is associated with decisions about the type and extent of infection control procedures by healthcare practitioners, based on the acceptance of some or no degree of risk which could limit professional activities, health and livelihood of the healthcare practitioner and/or those in their employment.

Negative collective views or stereotypes and moral judgments of those with HCV by healthcare providers, family, friendship networks and society serve as socially embedded controls that set the person apart from society. These social controls on individuals and populations with HCV are supported through the application of labels such as irresponsible, undesirable, deserving blame and even dangerous. A critical and associated attribute embedded in the transactions of those with HCV is the application of power by healthcare practitioners, family and friendship networks and society that facilitates the imposition of restrictions.

Antecedents of HCV stigma

Antecedents, summarized in Table 2, constitute the events that take place prior to the occurrence of stigma (Rodgers 2000). Antecedents occur at the individual level (the person with HCV and the healthcare practitioner) and the structural level (society). Antecedent events emanating from interpersonal encounters with family and friends, described in the data as rooted in societal views, are contained within the society category. Antecedents occur separately or cluster together and result in the perception and/or experience of stigma.

Hepatitis C virus stigma antecedents are most often events or situations where people with HCV attempt to have their care and/or support needs met. These events or situations occur most frequently in healthcare settings. During these events, there is a change in previous relationships or a mismatch between the perceived care and/or support needs of people with HCV and their actual experiences as compared with the care and/or support of those who do not have HCV.

Table 2 Summary of findings

Analysis component	Category	Elements
Attributes	1. General	Subjective; variable; perceived; experienced; intrapersonal; interpersonal; structural/institutional
	2. Disease-based (structural)	Associated with injection drug use (IDU); contagious; life-threatening
	3. HCP (individual/structural)	Fear of transmission; Level of acceptable risk; application of power; moral judgments
	4. Society (structural)	Negative stereotyping; moral judgments; labels
Antecedents	1. PWHCV (individual)	Diagnosis of hepatitis C (HCV); disclosure; ethical decision-making; emotional state; misinterpretation; vulnerability; sensitivity
	2. HCP (individual)	Lack of knowledge or experience with HCV
	3. Society (structural)	Lack of knowledge or experience with HCV; confusion with human immunodeficiency virus (HIV); unpredictability of disease course; pre-existing social and power inequalities
Consequences	1. PWHCV (individual)	A. Emotional (intrinsic) responses Distress, anxiety, fear, self-blame (shame), disappointment, alienated, feelings of loss (loss of control, ideal future, friendships), feeling set apart (leper, non-person, flawed), depression
		B. Problem-solving responses (extrinsic) Secrecy and avoiding help-seeking: barrier for receiving prevention information, care and treatment; narrows sources of social support; precludes non-stigmatizing experiences; and increases risk of greater discrimination Resistance: refusal to accept blame, disregarding stigma, refusal to comply with inappropriate infection control measures Image management: pre-emptive disclosure sometimes combined with teaching others about HCV to prevent the formation of negative personal judgments
		2. Social (interpersonal)
	2. Social (interpersonal)	A. Financial consequences: changes to employment (demotion, termination, transfer) and lack of access to insurance
		B. Personal relationships Exclusion and marginalization: harassment/ridicule and fear and guilt associated with being found out create relationship difficulties leading to social isolation (loss of physical contact and intimacy with others) and reduced support to live positively with HCV
		C. Health care Slow delivery of care, poor quality of care or refusal of services, as well as discrimination during services (unfair, changed demeanour or expressed negative attitudes, inappropriate infection control assigning labels, breach of confidentiality) resulting in dissatisfaction with and avoidance of care
3. Health system (structural/institutional)	A. Research about transmission slow to be employed in health policy, IDU ineligible for treatment despite lack of supporting clinical evidence increases the burden of disease and risk of transmission	
	B. Institutional discrimination evidenced in slow response to epidemic and release of funds for prevention and control and (contributes to the invisibility of disease)	

PWHCV, person with HCV; HCP, healthcare practitioner.

Commonly described antecedents are receiving a diagnosis of HCV or disclosure of HCV status. Receiving and/or sharing the diagnosis of HCV frequently precipitates a change in how people with HCV view themselves and how others view them. Disclosure is so significant that most people with HCV speak of learning very soon after receiving their

diagnosis to be discrete or secretive about disclosing to prevent stigma. An antecedent interrelated with disclosure is the purposeful ethical decision-making by people with HCV, e.g. when the duty to disclose (and its associated discomforts) is chosen over the need to protect one's privacy to protect others from exposure to the risk of transmission.

Emotional factors such as a negative outlook or depressed mood may lead to the interpretation of situations as stigmatizing. Additionally, a misinterpretation of the reason behind the actions of others may result in perceptions of stigma. A general lack of knowledge of and/or experience with HCV by healthcare practitioners and society is a frequently noted antecedent. Contributing factors related to knowledge are confusion between HIV and HCV and the unpredictability of chronic illness. Important but less frequently described antecedents at the societal level include pre-existing social and power inequities experienced by many of the populations at-risk of HCV. Those who are already vulnerable and/or sensitive to stigma are more likely to experience HCV stigma.

Consequences of HCV stigma

Consequences are the events or outcomes that result from stigma (Rodgers 2000). The consequences of HCV stigma are summarized in Table 2. Stigma outcomes occur in various forms and contexts and may be consistent or change over time. The compounding of stigmas, for example, from HIV, mental illness and addictions may increase stigma events in healthcare settings. Stigma events are frequently, but not universally, viewed as negative and stressful, leading to a variety of responses. The most frequently noted stigma events surround interpersonal interactions with healthcare providers, followed by events with family, friends and employers. Individual responses may have an emotional (intrinsic) and/or a problem-solving (extrinsic) orientation. Self-stigma results in emotional outcomes such as self-blame for being infected and deserving of punishment. The loss of social, economic and healthcare relationships results in feelings of being mistreated, rejected and abandoned. Loss of relationships also leads to social isolation, loss of income, declines in health, well-being and quality of life, reduced access to and avoidance of healthcare, as well overall increases in life stress and the burden of illness. On the other hand, losses sometimes result in reframing of the situation from acceptance of a loss to taking action for positive outcomes by educating, negotiating, planning defensive actions or replacement, e.g. finding new friends.

References

References constitute the range of events, situations or problems over which application of the concept is considered to be appropriate (Rodgers 2000). Stigma occurs within a wide range of diseases or factors in which individuals and populations are in a position of vulnerability to the power of others to

impose sanctions (Link & Phelan 2001). Stigma can take place at all levels of society: micro, meso and macro. The HCV stigma literature most frequently cites healthcare settings, followed by family, friends, employers and society as a whole.

Surrogate terms

Surrogate terms are terms that are used interchangeably to express the concept (Rodgers 2000). The recurring surrogate term 'discrimination' is used exclusively in the Australian studies included in the sample to emphasize the extension of and responsibility for stigma beyond the person with HCV. Prejudice was used as a surrogate term only once in the sample.

Exemplar

An exemplar is a case that is identified by the researcher to present a practical demonstration of the concept in a relevant context (Rodgers 2000). The literature on the concept of HCV stigma is emergent, the data being primarily from the perspective of one group, those with HCV. Examples to illustrate the perspectives of those with HCV were presented in the preceding section on attributes. Other dimensions associated with the concept, such as the structural and institutional aspects and the perceptions of important groups such as healthcare practitioners, remain largely unexplored. Given the limitations of the literature, it is premature to present an exemplar.

Discussion

Hepatitis C virus stigma is a subjective and variable, perceived and/or experienced phenomenon, most frequently but not exclusively perceived as negative, that has interrelated intrapersonal, interpersonal and structural or institutional dimensions. The scope and depth of this analysis is limited by a dearth of published research and its domination by the viewpoint of those stigmatized within Western countries. Input from multiple perspectives is necessary to complete the organization of knowledge and thought on complex phenomena such as HCV stigma. The concept of HCV stigma presented is thus preliminary, requiring further refinement and testing. Research in different cultural contexts from multiple perspectives would improve the theoretical formulation, leading to a mid-range theory to ground research and clinical practice. Uncovering the various factors or forces contributing to stigma could assist nurses to answer questions of accountability for the problems posed by stigma and help shape nursing interventions. To be useful, the present

conceptualization should be linked to nursing theories that include consideration of influences that are external to the person, such as Roy's theory of adaptation (Roy 1984), Neuman's theory of internal and external influences (Neuman 1995) and the recent complexity integration theory of Van Sell and Kalofissudis (2001).

Rodgers (2000) framework was very helpful in organizing and guiding the examination, exploration and synthesis of 15 years of published research. The ecological lens provided for exploration of stigma and its interrelationships beyond the level of the individual. Theories that encompass ecological perspectives could be used in future to expand the HCV stigma research agenda. For example, ecological theory could be paired with a complementary nursing theory to guide our understanding of how the forces of social and political stigmatization influence health service priorities, programmes and nursing interactions with people with HCV (Kickbusch 1986).

This concept analysis contributes to the literature by providing a synthesis and portrayal of the current status of the key attributes and contextual features (antecedents and consequences) of the concept of HCV stigma. The majority of examples of HCV stigma were associated with the provision of healthcare and attributed to healthcare practitioners' lack of knowledge of HCV, indicating the need for information and education about this relatively new disease. The other striking attributes frequently used to explain stigma perceptions and experiences in healthcare settings are the association of HCV with IDU and fear of transmission, which is linked to the acceptable level of risk.

The findings support the view that healthcare practitioners focus on the virus and its impact on the body and not on the psychosocial aspects of the disease (Minuk *et al.* 2005). The effects of failing adequately to assess the psychosocial environment in which illness is experienced (Hepworth & Krug 1999) and to understand what the experience and meaning of illness represents for the client (Kleinman 1988) are important considerations for nursing and other disciplines. In addition, the analysis highlights the importance of understanding the stigmatizing messages given to clients, whether intentionally or not, and how the burden of stigma affects people, so that stigma perceptions and experiences can be discussed with clients. For example, nurses sensitive to the emotional discomfort that disclosure of a HCV diagnosis may illicit can take care to establish rapport and trust before asking sensitive questions that could result in avoidance of care and progression of disease. Models of care taking into account the experience and meaning of illness and the social context of the individual need to be more fully employed.

This analysis provides information which can be used by nurses to determine whether changes to their clinical practice are required. For example, when nurses have a clear understanding of HCV stigma, it follows that it is more likely that changes to practice can be implemented to address appropriately the specific needs of those with HCV, including the provision of accessible and appropriate environments where those with HCV can feel safe and free from stigma.

The development and evaluation of health policy and health messages, in emphasizing particular behaviours such as sharing syringes that single out risk groups such as inmates in correctional facilities, is sometimes construed by people with HCV as stigmatizing. Messages that suggest that people with HCV are irresponsible or untrustworthy are likely to reinforce stigma. In addition, much like HIV, the notion of blame and responsibility is accentuated by the identification of 'innocent victims' (Albert 1986). Policies that provide special services for a subset of the HCV population, e.g. those infected through blood supply, often create stigma in this group that is not identified as a priority in the policies.

The concept analysis highlighted several limitations in our present knowledge of HCV stigma, many of which are similar to those in HIV stigma research. There is a lack of theory-informed HCV stigma research. Stigma is portrayed in the data largely through lay or colloquial understandings or definitions, rather than from a conceptual or theoretical lens. This feature is also analogous to HIV stigma research, which is characterized by a general lack of use of explicit definitions of stigma (Parker & Aggleton 2003).

The social construction of HCV stigma is strongly linked to a particular group, namely IDU, and bears striking similarities to the stigma of HIV, which was tenaciously associated with a particular group, i.e. homosexuals, in the early 1980s as knowledge of HIV began to emerge (Herek 1999). Another parallel to HIV is the pervasive and distressing nature of the stigma experience, the basis of stigma in a culture of fear of transmission, and negative social views of those participating in risky behaviours and belonging to devalued social groups (Green 1995, Gray 2004).

Unlike HIV research, which has focused on identifying the beliefs and attitudes of those who perform the stigmatizing (Parker & Aggleton 2003), HCV research has focused on the beliefs and experiences of those who are subjected to stigma, making comparisons between the two fields challenging. However, research in both HCV and HIV has been focused at the individual level and the designation that others attach to that individual, and little on the structural conditions that shape policies and practices (Link & Phelan 2001). Research is required to extend the current findings beyond the individual level, as interventions based on one perspective

What is already known about this topic

- Research on infectious diseases identifies stigma as an important problem leading to avoidance of healthcare services and negative health outcomes.
- The stigma of hepatitis C is a new field of research.
- Hepatitis C stigma is pervasive in healthcare settings.

What this paper adds

- Hepatitis C stigma, conceptualized from the perspective of those stigmatized, is a subjective and variable perceived and/or experienced phenomenon with intra-personal, interpersonal, and structural or institutional dimensions.
- A central and distinctive feature of hepatitis C stigma in the Western world is its association with illicit drug use.
- The stigma of hepatitis C presents major challenges not only for those with HCV, but also for nurses, other healthcare practitioners, family and social networks, institutions and society.

are considered insufficient to deal with the complexities of stigma (Paterson *et al.* 2007). For example, as Corley and Goren (1998) point out, practitioner behaviours persist through peer or institutional support, requiring attention to organizational culture and institutional policies that support respectful and non-judgmental care (Gordon *et al.* 2000). Research is needed that focuses on the structural forces of stigma and is based on a philosophical ontology that acknowledges the social construction of stigma within multiple realities. Research approaches, such as institutional ethnography, that encompasses the political, historical, sociocultural, and economic construction of stigma are also needed (Link & Phelan 2001).

Finally, the analysis revealed that individuals' responses to HCV stigma may vary over time. Alonzo and Reynolds (1995) propose that among those with HIV responses to stigma change in various phases of the illness experience or trajectory; this hypothesis should be considered for empirical investigation in HCV. For example, as diminished self-esteem is not an inevitable consequence of stigma (Butt *et al.* 2008), future research on how time modifies or changes the impact of stigma on the self-esteem of people with HCV could illuminate which antecedents, such as employment, gender or disease progression, influence outcomes. Research is also needed to determine the personal and contextual factors that foster positive responses to stigma by people with HCV.

Conclusion

The limited research on HCV stigma indicates that stigma presents major challenges not only for those with HCV, but also for nurses, other healthcare practitioners, family and social networks, institutions and society. HCV stigma is an emerging concept with relevance to the stigma of other infectious diseases; however, a central and distinctive feature of HCV stigma in the Western world is its association with IDU. Further research is required to understand the complexities associated with the sociocultural, situational and structural features that influence the stigma experience as well as the trajectory of the disease to better understand the concept and inform practice.

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