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Social Science & Medicine 63 (2006) 3188–3198

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Illness-related stigma, mood and adjustment to illness in persons with hepatitis C

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Available online 28 September 2006

Abstract

We examined stigma in persons with hepatitis C and its relationship with mood and adjustment to illness. We studied 87 persons awaiting interferon treatment for hepatitis C at St James's Hospital, Dublin. Stigma was assessed using Fife's Experience of Illness scale. A structured clinical interview was used to establish DSM-IV diagnosis. The Hospital Anxiety and Depression Scale (HADS) and Beck Depression Inventory (BDI) were also used as measures of mood. Factor analysis and clustering around latent variables analysis were used to assess scale structure and reliability. The stigma scale had an overall reliability of 0.94. A strong dimension of fear of disclosure emerged, from item analysis, together with dimensions of social isolation and social rejection. Stigma was higher in those in manual occupations and the unemployed than in those in non-manual occupation. There were high levels in those with disease associated with injecting drug use and iatrogenic disease caused by transfusion or anti-D blood products, and low levels in those who had been treated for haemophilia with contaminated products or whose hepatitis was of unknown origin. Adjusted for confounders, a 1-decile increase in stigma score had an odds ratio of 1.4 for DSM-IV depression and similar associations with depression on the HADS and BDI. Stigma was also associated with poorer work and social adjustment, lower acceptance of illness, higher subjective levels of symptoms and greater subjective impairment of memory and concentration. These associations were replicated in the non-depressed subsample. The results underline the strong link between stigma and well-being in hepatitis C. However, they also suggest that stigma is a complex construct that will require further research to elucidate.

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Keywords: Ireland; Hepatitis C; Depression; Stigma; Injecting drug use

Introduction

Hepatitis C poses a very significant health problem on a global scale (Hoofnagle, 1997).

Although the incidence of hepatitis C infection has dramatically decreased during the past decade (Chen & Morgan, 2006), the World Health Organization estimates the worldwide reservoir of chronically infected persons at 170 million (Marcellin, 1999), or 3% of the global population. Hepatitis C is now the leading cause of end-stage liver failure and the leading indication for liver transplant in the

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developed world. In the past decade, there has been a marked shift in the epidemiology of the disease. With infections due to contaminated blood products falling sharply due to improved blood screening, injecting drug users have become the primary source of new cases of infection. Studies of injecting drug users have shown prevalences of at least 30% while some cohorts have close to 100% prevalence (Schaefer, Heinz, & Backmund, 2004).

In February 1994 the Irish Department of Health announced through the media that Rhesus negative women who had received anti-D immunoglobulin post-partum between the years 1977 and 1994 had been potentially exposed to the Hepatitis C virus. A national screening programme was established and these women were invited to come forward. The Annual Report of the Irish Blood Transfusion Service Board for the year 2000 indicates that, to the end of December 2000, 65,980 women had come forward for screening, of whom 1026 were found to be positive for hepatitis C virus (1.6%) (Anonymous (Irish Blood Transfusion Service), 2001). The discovery and initial management of this health crisis has been described in the media as “the biggest public health debacle in the history of the Irish State”. It precipitated unprecedented media, legal and political attention resulting in the alteration of two statutes in Irish health legislation.

In addition to these women, a significant number of persons with haemophilia acquired hepatitis C through contaminated blood products. Many of these persons had also acquired HIV.

Persons with hepatitis C have high rates of psychological symptoms and reduced quality of life compared with the general population (Cordoba, Reyes, Esteban, & Hernandez, 2003; Coughlan, Sheehan, Hickey, & Crowe, 2002; Dieperink, Ho, Thuras, & Willenbring, 2003; Foster, Goldin, & Thomas, 1998; Rodger, Jolley, Thompson, Lanigan, & Crofts, 1999; Yates & Gleason, 1998; Yovtcheva, Rifai, Moles, & Van der Linden, 2001). The presence of depressive symptoms in hepatitis C, as in other chronic medical illnesses, is important because they have an adverse effect on the course of illness, with amplification of physical symptoms, functional impairment, reduced treatment compliance, and reduced quality of life (Dwight et al., 2000).

While high rates of mood disorder have been found in many studies, there is still little agreement

on reasons for this high prevalence. One factor which emerged strongly from a review of the health status of Irish persons with iatrogenic hepatitis C was illness-related stigma (McGee, Hickey, Smith, & Byrne, 2000). Although the study participants were asked only one stigma-related question, this single item proved the strongest single predictor of depression and anxiety, assessed using the Hospital Anxiety and Depression scale (HADS).

Illness-related stigma has received a growing measure of attention in the medical literature, with several measures being proposed. (Berger, Ferrans, & Lashley, 2001; Ritsher, Otilingam, & Grajales, 2003) The Experience of Illness scale by Fife (Fife & Wright, 2000) measures four dimensions of stigma: social rejection, financial stigma, internalised shame, and social isolation.

In this study we use the Experience of Illness Scale to conduct a fuller investigation of the relationship of stigma to a broad range of measures of psychological well-being and adaptation to illness in a group of persons with hepatitis C. These measures include both clinical and self-assessment of anxiety and depression. We also use the data to examine the factor structure of the stigma scale.

Methods

Participants

Participants were recruited from patients who were attending the hepatology and genitourinary infectious disease departments of St. James's Hospital, a university teaching hospital serving a predominantly deprived area of inner-city Dublin. We describe the study in more detail elsewhere (Golden, O'Dwyer, & Conroy, 2005). Potential participants were approached by telephone or in person at least 1 week before their scheduled outpatient visit and the study was explained to them. Participants were assessed after written informed consent to participate had been obtained. Ethical approval for the study was obtained from the St. James's Hospital Research Ethics Committee. Data were rendered anonymous using a sequential study number. Paper records linking study numbers to participant identity were destroyed when data entry was complete. Participants whose assessment revealed untreated psychiatric disorder were offered a referral to the relevant psychiatric services for treatment.

Measures

Stigma

We assessed stigma using the Experience of Illness Scale by Fife and Wright (Fife & Wright, 2000). This measure has 23 items, and assesses experience of stigma in the past 3–4 weeks, along four dimensions comprising social rejection (e.g. “Some family members have rejected me because of my illness”), social isolation (e.g. “I feel set apart from others who are well”), internalised shame (e.g. “I feel I need to keep my illness a secret”), and financial stigma (e.g. “My job security has been affected by my illness”).

Mood

Depressive and anxiety disorders were rated using the Structured Clinical Interview for DSM-IV Axis I Disorders: Clinician Version (SCID-CV; First, Gibbon, Sptizer, & Williams, 1996), which has been designed for use in clinical settings with either psychiatric or general medical patients. The interview allows for a diagnosis of current (within the previous month) and lifetime psychiatric disorder. In this paper, we have confined analysis to current disorder, to parallel the measure of stigma, which relates to the month prior to examination. Diagnostic interviews were carried out by the first author, a senior registrar in psychiatry, who was blind to the results of the self-administered measures. We also used two self-completion measures of mood: the HADS and the Beck Depression Inventory (BDI). These address two shortcomings of the SCID-CV. First, they measure mood on a continuous scale, allowing the detection of graded relationships between mood and stigma. Second, there is considerable concern that the current DSM-IV criteria for generalised anxiety disorder under-represent the prevalence, because it cannot be diagnosed in the presence of a depressive disorder (Gorman, 2001). The HADS anxiety subscale does not have this limitation and is therefore a more valid measure of anxiety disorders.

Adjustment to illness

We measured a number of aspects of adjustment to illness using self-completion measures. Work and social adjustment was measured using the Work and Social Adjustment Scale, a short scale developed by

Marks (Marks, 1986). Mundt and Marks report that the scale has high internal consistency and is sensitive to differences between patients in disorder severity and to treatment-related change within patients (Mundt, Marks, Shear, & Greist, 2002). Acceptance of illness was measured using Felton’s 8-item scale (Felton & Revenson, 1984; Felton, Revenson, & Hinrichsen, 1984) which assesses the extent to which respondents are able to accept their illness without experiencing negative feelings or responses. We devised simple self-rating scales to assess frequency and severity of hepatitis C symptoms within the two weeks prior to assessment, and subjective impairment of thinking and concentration.

Analysis

Data were analysed with Stata Release 9. Cronbach’s α was used to calculate scale reliability. Scales with arbitrary scoring ranges were converted to deciles to facilitate reporting of effect sizes. Principal factor analysis with varimax rotation was used to examine the factor structure of the stigma scale. We also examined the factor structure using Clustering around Latent Variables (CLV) analysis. CLV (Vigneau & Qannari, 2003) is a procedure which allows graphical inspection of item clustering. The CLV procedure was written by one of us (J-BH).

Results

Participants

There were 90 participants, of whom 3 failed to complete the stigma questionnaire, leaving 87 participants, of whom 23 were women. Table 1 shows background and clinical data on the participants.

The median age of the men was 44, significantly higher than that of the women, whose median age was 37. There was also a difference between the genders in the distribution of route of infection ($p < 0.001$): in each sex just under 20% were of unknown aetiology. Injecting drug use accounted for roughly half of the cases in men, against a quarter of the cases in women. There were 14 men with iatrogenic hepatitis C as a result of treatment for haemophilia with contaminated blood products, and a further five men who had acquired iatrogenic hepatitis C though transfusion. There were 11

Table 1
Characteristics of the participants

	Women	Men	All participants	<i>p</i> -Value
No of participants	23 (26.4%)	64 (73.6%)	87	
Age				
Median (25 percentile, 75 percentile)	44 (34, 49)	37 (32, 41)	38 (33, 43)	0.007*
Route of infection				
Unknown	17.4%	17.2%	17.2%	<0.001*
Iatrogenic:				
- anti-D or transfusion	56.5%	7.8%	20.6%	
- hæmophilia	0	21.9%	16.1%	
Injecting drug use	26.1%	53.1%	46.0%	
Social class				
Manual	39.1%	55.9%	51.2%	0.171
Marital status				
Married/cohabiting	65.2%	59.4%	60.1%	0.622

Significance levels based on χ^2 test or *Wilcoxon rank sum test.

women with iatrogenic hepatitis C, of whom all but two had received contaminated anti-D immunoglobulin. The participants were divided almost equally between manual and non-manual social classes, and about 60% lived with a partner.

Test performance of the stigma scale

We first examined the psychometric properties of the stigma scale. The stigma scale had an overall reliability of 0.94 (Cronbach's α). A factor analysis followed by varimax rotation showed a factor structure that differed in some respects to that described by Fife (Fife & Wright, 2000). Three factors emerged: eight of the nine items of the original social rejection subscale shared factor loadings. The second factor comprised the original social isolation items, together with the three items of the financial stigma subscale. Finally, three items from the internalised shame subscale formed a factor reflecting fears about disclosure: "I cannot be open about my illness", "I fear someone telling others" and "I need to keep my illness a secret". The CLV analysis identified three major item clusters. The analysis is displayed graphically in Fig. 1. It shows clusters reflecting social rejection (top), social isolation—which included the items from the financial stigma subscale (centre), and fears about disclosure (bottom). These are similar to the factors which had emerged from the factor analysis. Note that the figure shows abbreviated wording of the scale items.

Variation in stigma scores among participants

Examination of normal quantile and normal probability plots revealed a good approximation to the normal distribution in the total stigma scores. We examined the effect of gender and route of infection on stigma scores using analysis of variance. Women and men had similar levels of stigma ($p = 0.600$). Route of infection was significantly associated with stigma score ($p < 0.001$). The lowest scores were in the participants who had disease of unknown aetiology. However, the men who had acquired hepatitis C through treatment for hæmophilia were not significantly different to those of unknown aetiology ($p = 0.492$). Those whose hepatitis C was associated with injecting drug use had the highest stigma scores ($p = 0.002$ compared with those of unknown aetiology). Those who had contacted hepatitis C through contaminated anti-D or blood transfusions had scores which were significantly higher than the unknown aetiology group ($p = 0.004$), but were not statistically significantly different to the IVDU group (Wald post-hoc test $p = 0.740$). Thus two groups emerged: levels of stigma were lower in persons with hæmophilia and those with hepatitis C of unknown aetiology, while persons with hepatitis C from anti-D or transfusions, or from injecting drug use had higher scores.

Stigma scores were also lower in the non-manual social classes ($p = 0.021$, adjusted for gender and route of infection). Being unemployed was also

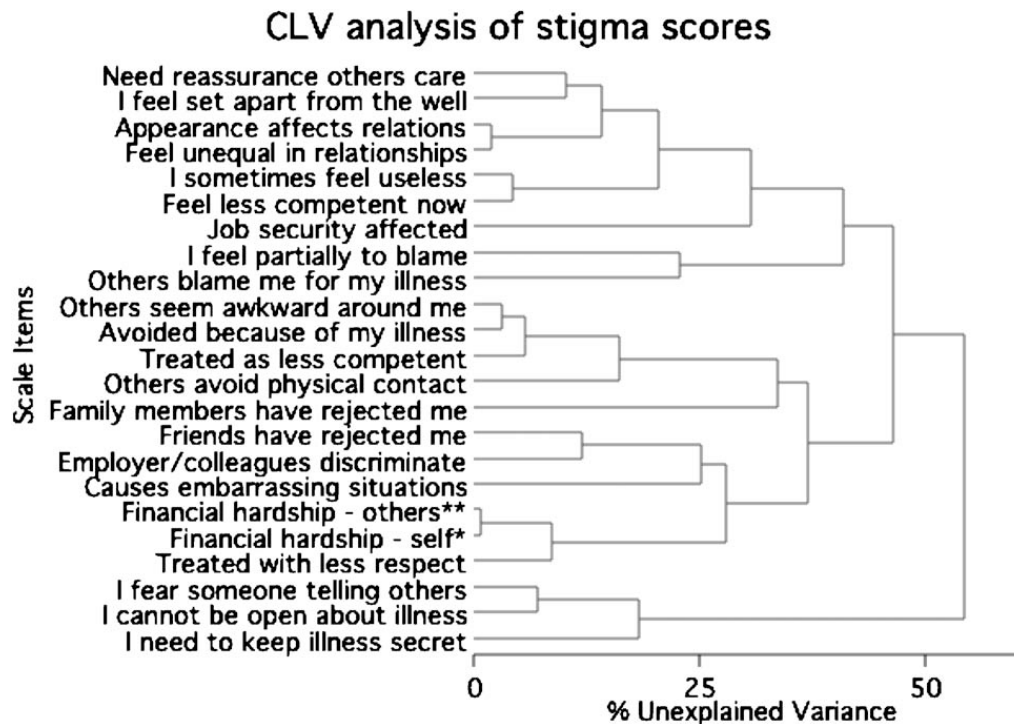


Fig. 1. Structure of the stigma scale using clustering around latent variables (CLV) analysis. *Note:* wording of all items shortened from their original form *Financial hardship has affected how feel about myself. ** Financial hardship has affected my relationships with others.

Table 2
Mean decile of stigma score predicted by multiple regression

Route of infection	Social class and gender			
	Non-manual		Manual	
	Men	Women	Men	Women
Unknown	2.8	3.5	4.2	5.0
Haemophilia	2.2		3.7	
Anti-D Transfusion	5.3	6.1	6.8	7.5
IVDA	5.5	6.3	7.0	7.8

associated with higher stigma scores ($p = 0.017$). However, unemployment and manual social class were highly correlated (χ^2 test, $p = 0.013$) and when both were included in the analysis, each was of borderline statistical significance ($p = 0.084$ and 0.086 for non-manual social class and unemployment respectively). Adjusted for route of infection, gender, and social class there was no statistically significant association between marital status (living with or without partner) and stigma scores.

Because stigma is measured on an arbitrary scale, we rescaled the original scores as deciles. Table 2 shows the mean decile scores, calculated by multiple regression, in men and women, for the four main

routes of infection and the two major occupational classes.

It should be noted that these deciles are predicted from multiple regression, and not those observed, as some of the subgroups in the data contain very few observed cases. It is notable that the scores of the anti-D and transfusion group are very similar to those of the injecting drug use group, while the scores of the men in the haemophilia group are similar to men in the unknown aetiology group.

Stigma and mood disorders

Depression

Twenty-five participants (28.7%) received a DSM-IV clinical diagnosis of current depressive disorder based on the clinical interview. Of these, seven met criteria for major depressive disorder, ten for adjustment disorder with depressive features and eight for dysthymia or depressive disorder not otherwise specified. Twenty-four participants (27.6%) were classified as probable cases on the depression subscale of the HADS. BDI scores can be categorised as normal, mild, moderate, and severe depression. Thirty participants (34.5%) scored in the normal range on the BDI and a further 19 (21.8%) in the mildly depressed range.

We pooled the moderate and severe categories to identify participants who were significantly depressed on the BDI. Thirty-eight participants (43.7%) scored in the moderate and severe categories.

Anxiety

There were 21 participants (24.1%) who met DSM-IV criteria for anxiety disorders, of whom eight had a comorbid depressive diagnosis. Ten of the participants with anxiety disorder had panic or phobic disorders, six had adjustment disorder with anxiety features, one had obsessive compulsive disorder and the remainder had anxiety disorder not otherwise specified. No participant met criteria for generalised anxiety disorder. Forty-two participants (48.3%) were identified as probable cases on the HADS anxiety subscale.

Table 3 shows the odds ratios for depression and anxiety, using both clinical and self-administered ratings, and stigma scale scores. The odds ratios are expressed for a 1-decile increase in stigma scale scores. We carried out two logistic regression analyses, a univariate analysis and a multivariate analysis in which the odds ratio was adjusted for age, sex, route of infection, and non-manual social class.

Stigma scale score was associated with depression, using any of the three criteria for caseness, in both univariate and multivariate models. Adjusted for age, gender, route of infection and social class, risk of DSM-IV depression was 8% in the lowest decile of stigma scores while it was 68% in the highest decile. Similar gradients were seen for caseness on the BDI, where risk rose from 1% in the first decile of stigma scores to 98% in the highest

decile, and on the HADS, where risk rose from 3% to 81%.

Risk of caseness on the HADS anxiety subscale rose from 14% in the lowest decile of stigma scores to 92% in the highest decile, adjusted for age, sex, route of infection, and social class. However, stigma was not associated with an increased risk of a DSM-IV anxiety diagnosis.

Stigma and experience of illness

We examined the relationship between stigma scores and experience of illness. Table 4 shows the effect of a 1-decile increase in stigma scores on scores on these measures.

Higher levels of stigma were associated with poorer scores across all measures of experience of illness: poorer work and social adjustment, lower acceptance of illness, higher reported frequency of symptoms of hepatitis C and greater perceived impact of these symptoms on the participant’s ability to live normally, greater reported impairment of memory and of concentration. These associations were independent of age, gender, route of infection, and non-manual social class. Because perceptions of illness and of adjustment might be coloured by the presence of depression, which is strongly associated with stigma, we repeated this analysis for those who had no DSM-IV depressive diagnosis. All of the associations were statistically significant in this subgroup.

Table 3
Odds ratio (95% CI) of having a mood disorder associated with a 1-decile increase in stigma scale score

	Odds ratio	95% CI	Adjusted odds ratio ^a	95% CI
Caseness criterion for depression				
DSM-IV	1.4	(1.2–1.8)	1.4	(1.1–1.8)
BDI	1.8	(1.4–2.3)	3.1	(1.8–5.2)
HADS	1.5	(1.2–1.9)	1.8	(1.3–2.4)
Caseness criterion for anxiety				
DSM-IV	1.0	(0.9–1.2)	1.2	(0.9–1.5)
HADS	1.5	(1.2–1.8)	1.6	(1.2–2.1)

^aAdjusted for age, sex, route of infection, and non-manual social class.

Table 4
Effect of a 1-decile increase in stigma score on decile scores of measures of illness adjusted for age, sex, route of infection, and non-manual social class

Measure ^a	Effect of a 1-decile increase in stigma score	95% CI	p-Values
Work and social adjustment ^b	0.68 ^b	0.46 to 0.89	<0.001
Acceptance of illness	–0.71	–0.89 to –0.52	<0.001
Frequency of symptoms	0.42	0.12 to 0.66	0.003
Impact of symptoms	0.35	0.09 to 0.60	0.008
Impairment of memory	0.44	0.17 to 0.72	0.001
Impairment of concentration	0.55	0.28 to 0.85	<0.001

Note. p-values are based on multiple regression on the original values of the variables, adjusting for age, gender, route of infection, and non-manual social class.

^aRecoded into deciles to facilitate comparison between measures.

^bHigher scores indicate poorer work and social adjustment.

Fears around disclosure. We also examined fears around disclosure of illness by summing the three items (14–16) that formed the second factor extracted in our analysis. The lowest scores were in the participants whose hepatitis C was of unknown origin. Those who had acquired the illness iatrogenically had significantly higher scores than the former group ($p = 0.044$) while those who had acquired it through injecting drug use had intermediate scores, not significantly different to either of the other groups. Examination of the associations between mood and quality of life and fears around disclosure revealed similar relationships to those found with total stigma score (data not shown).

Discussion

Psychological well-being in hepatitis C

In this study, individuals with hepatitis C had high rates of psychological symptoms. This finding is consistent with other published research (Cordoba et al., 2003; Coughlan et al., 2002; Dieperink et al., 2003; Foster et al., 1998; Golden et al., 2005; Kraus, Schafer, Faller, Csef, & Scheurlen, 2003; Rodger et al., 1999; Yates & Gleason, 1998; Yovtcheva et al., 2001).

Furthermore, our findings underline the important role of stigma as a mediator of clinical and self-rated mood disorder in persons with hepatitis C. Adjusted for age, gender, route of infection, and social class, risk of DSM-IV depressive disorder and of caseness on the HADS and BDI scales rose sharply with increasing levels of stigma. In the case of DSM-IV depressive disorder, risk rose from less than 10% to over 60% between the lowest and highest deciles of stigma. Likewise, risk of caseness of the HADS anxiety subscale rose from 14% to over 90%. The failure to find an association with DSM-IV anxiety may well be due to the restrictive criteria for the diagnosis of generalised anxiety disorder and the exclusion of the diagnosis in presence of major depressive disorder (Gorman, 2001).

Furthermore, there was a similar strong relationship between stigma and all other aspects of adjustment to illness which we measured, with poorer work and social adjustment, lower acceptance of illness, higher frequency and perceived impact of symptoms, and greater perceived impairment of thinking and concentration in those with higher levels of stigma. These associations held well

in the subgroup of participants who did not have depressive disorder, suggesting that they are not simply an artefact of depressive cognitions.

The role of stigma in hepatitis C

While there has been a significant amount of research into the causes of the high rates of mood disorder and low quality of life in hepatitis C, much of it has focussed on attempts to establish a link between hepatitis C viral infection and mood and well-being. The results have been largely negative and, in a review of this literature in 2002, Wessely (Wessely & Pariente, 2002) concluded that “although there are elegant theoretical mechanisms, there is no compelling epidemiological evidence for an additional HCV specific fatigue or depression factor.”

It has also been proposed that the elevated levels of psychiatric morbidity seen in hepatitis C are due to the high levels in the population subgroups in which hepatitis C tends to occur. The group most at risk of hepatitis C, namely current and former injecting drug users, has an increased risk of psychiatric disorder independent of hepatitis C status, due both to their socio-demographic characteristics and to the high prevalence of antisocial personality disorder which is a risk factor for both mood disorder and for hepatitis C. (Dinwiddie, Reich, & Cloninger, 1992) However, we have previously reported similar rates of mood disorder in persons with hepatitis C who do not come from such population groups (Golden et al., 2005).

An alternative explanation involves the stigma involved in the diagnosis of hepatitis C. Coughlan (Coughlan et al., 2002) reported similar rates of depression in those who had chronic hepatitis C and in those who had evidence of previous acute infection only suggesting that the process of diagnosis rather than the disease itself was responsible. Similarly Rodger (Rodger et al., 1999), in her study of former intravenous drug users, reported that those who were aware of their HCV positive serostatus reported lower quality of life on the SF-36 than people with comparable liver disease who were unaware of their diagnosis. These and similar findings led Cordoba (Cordoba et al., 2003) to propose that disease labelling was central to the adverse psychological profile of persons with hepatitis C.

Identifying and labelling human differences is the first of five components of stigmatisation, proposed

by Link and Phelan (Link & Phelan, 2006). Medical conditions vary widely in their social significance. The experience of receiving a diagnosis of hepatitis C appears to be particularly psychologically painful and is associated with high levels of anxiety assessed using the HADS (Gill, Atiq, Sattar, & Khokhar, 2005). Hepatitis is associated with ideas of “dangerous blood” and blood which must be withheld from circulation (Treloar & Fraser, 2004; Waldby, Rosengarten, Treloar, & Fraser, 2004), and, hence, can be a powerful factor in generating a sense of irrevocable contamination (Fraser & Treloar, 2006).

Scambler (1998) makes a valuable distinction between enacted stigma, which is the actual discrimination that occurs, and felt stigma, which is the fear of such discrimination. Even in the absence of disclosure, felt stigma may be powerfully disruptive of people’s lives. Because of the considerable social significance of the diagnosis, non-disclosure is a first line of defence in what Goffman refers to as “impression management” (1959). Disclosure is a significant concern for persons with hepatitis C (McGee et al., 2000; Black & Miles, 2002; Max Hopwood, & Treloar, 2003; Petrak, Doyle, Smith, Skinner, & Hedge, 2001). In one study of over 400 people with hepatitis C, over a third regretted telling someone about their infection (Max Hopwood, & Treloar, 2003).

In view of this, it is not surprising that a dimension of fears surrounding disclosure emerged from both the factor analysis and the cluster analysis of the stigma scale. The highest levels of fears surrounding disclosure were in those with iatrogenic disease and the lowest in those with disease of unknown origin. Dunne, in her study of Irish women with iatrogenic disease, points out that they were simultaneously under a pressure to speak out about their illness in order to achieve redress, and at the same time fearful of the social consequences of disclosure (Dunne & Quayle, 2002) making disclosure a less controllable and more stressful process.

The second and third components of stigma, in Link’s formulation, involve stereotyping, in which the labelled person is linked to undesirable characteristics, and the separation of the stigmatised group in what Link characterises as a “them and us” relationship. This process is strikingly illustrated by Varas-Díaz and Toro-Alfonso’s (2003) analysis of newspaper images depicting HIV. They identify strong themes of protecting society by identifying

and isolating those with HIV. Our analysis of the structure of the stigma scale confirms the importance of the experience of social isolation and social rejection as key components of stigma. Hepatitis C is also associated with injecting drug use, and therefore will serve to label the person’s conduct as deviant. For this reason, iatrogenic hepatitis C carries the danger of stigma by misrepresentation. In our hospital service, the women infected with anti-D products were at pains to distance themselves from the injecting drug use patient group. The medical services facilitated this by organising outpatient services for the two groups on different days.

In the fourth component, stigmatised people experience discrimination and loss of status. It is clear from studies of the treatment of those with hepatitis C that discriminatory treatment is common, not least at the hands of the medical profession, and that this discrimination is more marked in those who also carry the stigma of injecting drug use. Medical services are slow to be delivered, with studies reporting as many as half of patients not being referred for specialist assessment or in continuing care with their family doctor (Gifford, O’Brien, Bammer, Banwell, & Stoope, 2003; Gifford et al., 2005).

One important aspect of the double stigmatisation of associated with injecting drug use is the recommendation in current guidelines for the use of interferon treatments of both the National Institute of Health (Anonymous, 1997) and the European Association for the Study of the Liver (Anonymous, 1999) which advise against treatment of those who are current or former drug users or who have a history of depression. As Schaefer recently pointed out, there never was any clinical evidence base for such recommendations, and he argues that this discrimination has been an important reason why 50% of patients who are eligible for interferon treatment remain untreated (Schaefer et al., 2004). This is supported by the finding that a significant proportion of injecting drug users do not seek treatment because they believe—probably correctly—they will not receive it (Doab, Treloar, & Dore, 2005).

Correlates of stigma

We were also able to examine variation in stigma levels between participants. There were higher levels of stigma in those in manual social classes and among those who were unemployed. These findings are similar to the associations observed by

Zickmund and her colleagues (Zickmund, Ho, Masuda, Ippolito, & LaBrecque, 2003).

However, the most significant finding was the variation in stigma levels between those with hepatitis C of different aetiologies: high levels occurred in those who had acquired hepatitis C through injecting drug use, and in those with iatrogenic disease caused by contaminated transfusions or anti-D products. The lowest levels occurred in those with iatrogenic disease associated with treatment for haemophilia and in those with disease of unknown origin. High levels would be expected in the injecting drug use group, since they have the double stigma of an infectious disease associated with behaviour perceived as socially deviant. Those with iatrogenic disease had only the stigma of the disease itself, since the infection was unconnected with their behaviour. They should therefore have had lower levels of stigma. This was true in the case of those with disease of unknown origin and those with haemophilia. However, the high levels of stigma in those who had acquired hepatitis C through contaminated anti-D or transfusions suggests that the different circumstances of the detection and management of the disease may have played a role in generating the heightened sense of stigma.

Those with haemophilia had a strong mutual support network and had an ongoing supportive relationship with medical services at the time when their hepatitis C and, in some cases, HIV were detected. In contrast, those who received contaminated transfusions or anti-D in pregnancy were detected as a result of a mass tracing programme which had a negative impact on psychological well-being and quality of life (Coughlan et al., 2002). The psychological distress resulting from the manner in which the women were infected and the manner with which the issue was subsequently managed was widely reported in the media and is dealt with in some detail in the Report of the Tribunal of Inquiry (Finlay, 1997). They mounted an energetic campaign for justice, compensation and treatment resources which resulted, amongst other things, in the provision of dedicated hepatology facilities in the hospital in which the study was based. However, this very campaign may also have increased a sense of stigma in the women in two ways: by putting pressure on the women to declare their disease status publicly (Dunne & Quayle, 2002), and by fostering a powerful sense of justice denied.

Conclusions

Our results demonstrate the considerable burden of stigma in persons with hepatitis C. We found strong associations between the experience of stigma and a wide spectrum of health outcomes, spanning the range from poor adaptation to illness to frank psychiatric disorder in hepatitis C. The structure of perceived stigma, involving social isolation, social rejection and fears surrounding disclosure, are somewhat different to those reported by Fife in HIV/AIDS and cancer, confirming that both the nature of the illness and the cultural context play a role in defining stigma. Through its links with decreased psychological health, reduced treatment seeking and treatment access, poor treatment compliance and even with reduced treatment success, stigma has serious consequences for many people (Jamison, 2006). Research on stigma is central to the effective prevention, detection and management of hepatitis C.

Acknowledgements

We are grateful to the staff of the GUIDE and hepatology services of St. James's Hospital who facilitated this research in many ways. We must also record our gratitude to Carla Treloar and Max Hopwood for their help.

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