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Stigma and Liver Disease

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STIGMA AND LIVER DISEASE

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ABSTRACT
This study explores stigma experienced by women with the autoimmune liver disease Primary Biliary Cirrhosis (PBC). Liver disease is commonly stigmatized due to an association with alcoholism and drug abuse, and persons with PBC may be subjected to stigma even though there is no etiological connection to substance use. Women with PBC (25 waiting list, 75 post-transplant), recruited through an online organization and two transplant centers, completed a survey regarding demographic, biomedical, psychological, and social contributors to overall quality of life (QOL). Two measures of stigma were analyzed in relation to the other variables and QOL. Open-ended questions concerned stigmatizing experiences and participants’ reactions to them. Almost one in five reported experiencing stigmatizing behaviors from others, in particular from medical professionals, that resulted in hurt and
anger. Higher stigma scores were associated with diminished mental and social dimensions of QOL as well as with greater uncertainty about illness, more symptoms from the disease and medication effects. Depression, fatigue, and age (younger) were key predictors of stigma. Those experiencing stigma should receive support and access to counseling. The knowledge and sensitivity of the public and medical professionals regarding the damage inflicted by stigmatizing any disease should be addressed through professional continuing education programs and public campaigns by organizations that support people with chronic liver disease.

**Key Words:** stigma, primary biliary cirrhosis, liver transplant, quality of life

**BACKGROUND**

Primary biliary cirrhosis (PBC) is a chronic, slowly progressive, liver disease of autoimmune etiology characterized by injury of the intrahepatic bile ducts that may eventually lead to liver failure. Affected individuals are usually in their 5th to 7th decades of life at the time of diagnosis, and 90% are women (Parikh-Patel, Gold, Mackay, & Gershwin, 1999). The cardinal symptoms are fatigue and pruritus (itching). Diagnosis is based on a combination of clinical features such as cholestatic liver enzyme abnormalities, a positive serological test for anti-mitochondrial antibody (AMA), and findings of proliferative cholangitis from liver biopsy (Lindor, Gershwin, Poupon, Kaplan, Bergasa, & Heathcote, 2009).

Liver transplantation (LT) is usually an option for patients with features of liver failure, although symptoms of intractable pruritus and chronic fatigue may significantly impact quality of life and thus also merit consideration for transplant listing (Garcia, Garcia, McMaster, & Neuberger, 2001). In women who have had liver transplants in the United States, PBC is the second most common diagnosis after Hepatitis C (OPTN online database, 2009), and it has a more favorable LT outcome than most other etiologies (Jacob, Bahra, Schmidt, Schumacher, Weimann, Neuhaus, et al., 2008; Maheshwari, Yoo, & Thuluvath, 2004). It is estimated that about 20-25% of patients undergoing LT for PBC will develop recurrent disease over the ensuing 10 years, which fortunately does not affect long-term patient or allograft survival (Sylvestre, Batts, Burgart, Poterucha, & Wiesner, 2003).

PBC has a strong genetic basis, is often associated with other autoimmune disorders, and is thought to be triggered by environmental factors (Gershwin & Mackay, 2008). Despite this etiology, the fact that it is a type of liver disease may lead to the assumption by others that PBC is due to use of alcohol or illegal, intravenous drugs, as may be the case with some other types of liver diseases.
In general, alcohol and drug users are viewed negatively, with the lay public attributing their behavior to poor judgment and immorality, and both the public and health professionals questioning whether they deserve priority for medical care (Neuberger, 2007; Neuberger, Adams, MacMaster, Maidment, & Speed, 1998; Room, 2005). Attribution of PBC to alcohol and substance use, mistaken assumption notwithstanding, often becomes justification for stigmatizing behavior toward the person with PBC. In this article, we explore the experience of PBC-related stigma and its effects on overall quality of life.

CONCEPTUALIZING STIGMA

Stigma is conceptualized as a powerfully negative way of perceiving or acting toward someone that underlies beliefs and practices of individuals, resulting in social discrimination or prejudice and having deleterious impact on those targeted (Butt, Paterson, & McGuinness, 2008; Link & Phelan, 2001). Stigma is often directed toward specific populations as a whole, such as seen in post-World War II studies of prejudice (Adorno, Frenkel-Brunswik, Levinson, & Sanford, 1950). Similarly, Goffman’s (1963) classic work discusses “the tribal stigma of race, nation, and religion.” Goffman also applied the concept of stigma to individuals with visible physical disabilities and those who are judged to have “blemishes of individual character.”

In recent years, there has been increased attention to stigma in relation to illness. Much of this research was prompted by the HIV/AIDS epidemic, since people with HIV/AIDS often represent both discredited populations and persons with disease-related characteristics that may prompt stigmatizing reactions (Herek, 1990; Nyblade, 2006). Stigma also presents challenges for persons with other illnesses (Levisohn, 2002) including epilepsy (MacLeod & Austin, 2003) and multiple sclerosis (Grytten & Maseide, 2006).

A small number of studies has addressed stigma with chronic liver disease generally (Gralnek, Hays, Kilbourne, Rosen, Keffé, Artinian, et al., 2000; Kraus, Schafer, Csef, Scheurlen, & Faller, 2000) and with Hepatitis C specifically (Butt et al., 2008; Golden, Conroy, O’Dwyer, Golden, & Hardouin, 2006; Grundy & Beeching, 2004). Hepatitis C infection is most often transmitted by intravenous drug use; the negative response by others can be due to (thought not excused by) the generalized stigma associated with illegal drug abuse.

Until now, no study has examined the experience of stigma for those with PBC, a chronic liver disease with no basis in etiology for the stigma associated with alcohol and drug use. Examining stigma experienced by those who have a disease without any link to alcohol or drug use can reveal public assumptions about blame. It also allows us to consider if recipients of stigma who are blamed for drinking or drug use may internalize the experience and be harmed by it, despite knowing it is not so.
Dimensions of Stigma

Those who have conceptualized stigma tend to have multi-faceted paradigms that include two or more of the following: the message or stigmatizing behavior, characteristics of the sender, characteristics of the receiver, context (such as chronic illness), and consequences (such as discriminatory practices and recipient hurt or shame). Van Brakel's (2006) review of disease-related stigma also noted institutionally-based stigmatizing practices such as in medical, legal, and educational domains.

Stigmatizing actions may be direct, such as in discriminatory employment practices or devaluing comments, or they may take more subtle forms, such as when the recipient senses that conversations cease when he/she enters a room (Bunn, Solomon, Miller & Forehand, 2007). Rather than risk rejection, and other interpersonal threats such as being judged incompetent, fear of ridicule, and abandonment, potential recipients of stigma may become reluctant to disclose their illness status or avoid social gatherings, leading to isolation (Dunne & Quayle, 2002; Fife & Wright, 2000; Hayes, Vaughan, Medeiros, & Dubuque, 2002; Pyne, Kuc, Schroeder, Fortney, Edlund, & Sullivan, 2004).

Stigma and PBC

Public knowledge about PBC is minimal; when people learn that it is a liver disease, they often falsely assume it is due to alcohol or other substance use and may express negative attitudes (Wainwright, 1997). This article explores the meaning of stigma for those with PBC; since at least 90% of people with PBC are women, we chose to recruit women only. The research addresses the following questions:

1. To what extent do women with PBC experience stigma?
2. What factors contribute to some women with PBC experiencing greater stigma than others?
3. For those women who experience stigma as a negative force in their lives, does this lower their overall quality of life?

We expect that the answers to these questions will support recommendations for practices to reduce stigma and improve quality of life.

Methods

The exploration of disease-specific stigma in this article derives from a larger study of PBC and quality of life (Lasker, Sogolow, Short, Sass, & Weinrieb, 2010). Women with PBC who were on a waiting list for transplant (WL) or who were post-transplant (PT) were recruited from:

1. the online PBCers Organization;
2. the University of Pittsburgh Medical Center; and
3. the University of Pennsylvania Health System.
The project was approved by each of the medical school IRB’s as well as by Lehigh University’s IRB (ORSP 05/86, 2/25/05) and by the Board of Directors of the PBCers Organization.

In the study, a biopsychosocial model for understanding the factors that influence quality of life with PBC was developed based on the literature and was used to generate hypotheses, guide survey construction, and organize data analysis (see Figure 1). Participants answered questions about demographic, biomedical, psychological, and sociological factors. Descriptions of the variables and their measurement can be found in Appendix A. All factors were posited to shape quality of life. Health related QOL (HRQoL) was assessed with the SF-36’s Physical Component and Mental Component Summary Scores (PCS and MCS) (Ware, Kosinski, & Dewey, 2000); social QOL was determined by scores on a measure of involvement in family and social life created for this study. Of note, no attempt is being made here to test the model, which is being used for heuristic purposes to help elucidate what factors shape QOL for those living with PBC.

Lasker et al. (2010) found no difference in perceived stigma between WL and PT groups, but significant relationships between stigma and some elements of quality of life outcomes were identified. The current article conducts a more in-depth examination of stigma in this sample.

To explore the experience and meaning of stigma in PBC, we used multiple measures, both quantitative and qualitative. Given the sensitivity of stigma and the limited prior research, this use of multiple methods and instruments allowed for a better understanding of the experience in this population.

For quantitative study, we selected two measures validated in prior studies but not used in populations with PBC. The first one is the stigma subscale of a larger instrument, the Liver Disease Quality of Life measure (LDQOL). It has six items, with responses on a 5-point Likert scale ranging from Strongly Disagree to Strongly Agree with a neutral mid-point (Gralnek et al., 2000). The second was adapted from a 40-item HIV Stigma Scale (Berger, Ferrans, & Lashley, 2001). To fit the current study, we substituted “liver disease” for “HIV” in each of the questions and added an item on the association of liver disease with alcohol abuse. The responses were on a 4-point Likert scale from Strongly Disagree to Strongly Agree, with no neutral mid-point.

Berger and colleagues identified four subscales: Personalized Stigma, Disclosure, Negative Self-Image, and Public Attitudes. Bunn et al. (2007) critique Berger’s subscales for not offering distinct dimensions of stigma, since individual items were assigned to multiple subscales, leading to a high inter-correlation among subscales. Our initial analyses supported the lack of distinction among subscales and thus only the total score is used.

The LDQOL and the HIV Stigma Scale instruments both appeared to be useful measures, and use of both allowed consideration of concurrent validity as well as validation with a PBC sample. Further, we asked the following
Figure 1. Quality of life in primary biliary cirrhosis: a biopsychosocial model.
questions: "Have you ever been in a situation(s) where you felt stigmatized because of your PBC?" (yes or no). "If yes please describe what happened in one specific situation. If you have had a transplant, indicate whether this occurred before or after the transplant." And "How did you feel in this situation?" The opportunity was provided to give two examples and describe feelings in response to each.

Data Analysis

The total scores for the LDQOL stigma scale and the adapted HIV Stigma Scale were analyzed descriptively for the group as a whole. For bivariate analyses, Pearson correlations were carried out, separately for the WL and PT groups, to examine the association between stigma and other variables in the model that might influence QOL, and also between stigma and QOL outcomes. For multivariate analysis, we used stepwise linear multiple regression in order to identify which were the most important biopsychosocial variables in the model (not including QOL measures) in relation to stigma.

Following paradigms referenced above that conceptualized stigma in terms of characteristics of the sender and consequences for the receiver, responses to the open-ended questions on stigma were content analyzed for source of the stigma experience (friends, strangers, and health professionals) and for how recipients felt about the experiences. The unit of analysis was each entire response. Two raters independently coded each item, with 98% inter-rater reliability. Differences were readily resolved by discussion.

RESULTS

Characteristics of the Sample

A total of 100 women, mean age 58.5, participated in the survey, 25 on waiting lists and 75 post-transplant. Participants in the study received care at over 50 different transplant centers. They ranged in age from 28 to 79, although the majority (82%) were in their 50s and 60s. Time since diagnosis of PBC ranged from 1 to 31 years, with a mean of 13.5 years. Of those who had had a transplant, the time between the surgery and participating in the survey ranged from less than 1 year to more than 17 years, with a mean of 5.23 years.

Of the 100 respondents, 68 were recruited through the PBCers website and 32 by their medical center. To check against possible bias based on recruitment source, comparisons were carried out; those recruited through the PBCers organization were younger than those from the medical centers, but they were no different on any other of the predictor variables in the model. Due to the similarities between the two groups, participants recruited from different sources were combined for analysis.
Quantitative Analyses

Analyses of the Stigma Scales

For the LDQOL and adapted HIV Stigma scales, Cronbach's $\alpha$ scores were .878 and .960, respectively, indicating strong internal consistency reliability of the scales with this sample. The scales were also significantly correlated with each other ($r = .603$, $p = .000$). Figure 2 displays the means, standard deviations, and distributions of scores, showing that these data were skewed toward the lower end for both measures. Fifteen percent of the sample had average item scores on the LDQOL measure of 3 (the mid-point) or above; only 3% of the sample had comparable results (average 2.5 or above) for the adapted HIV Stigma

Figure 2. Distribution of scores on adapted HIV Stigma Scale sigma scale.
scale (see Figure 3). The difference may be accounted for in part by the larger number of items on the adapted HIV Stigma Scale; while many participants agreed with a few items, as noted below, only a few agreed with most items.

Specific items and their average scores are found in Appendix B. Of interest is the high agreement (63.8%) with the statement, "In many areas of my life, no one knows that I have liver disease," suggesting a reluctance to disclose the illness, and 38.5% agreeing that "People who hear I have liver disease assume I am an alcoholic or drug user." Other items on which more than 20% of the sample agreed include: "I avoid doing some things in public because of my liver disease," "Most people are uncomfortable around someone with liver disease," and "Because of my liver disease, I feel flawed and incomplete."

Of the 94 who responded to the question about having ever been in a situation in which they felt stigmatized due to having PBC, 18 (19.1%) indicated that they had had such an experience. In examining results for both the scales and the question on stigmatizing experiences, we note that 27 women out of 100 either reported a stigmatizing experience or had scores on one of the subscales indicating agreement, or both.

Figure 3. Distribution of scores on LDQOL sigma scale.
<table>
<thead>
<tr>
<th>Demographic</th>
<th>LDQOL Stigma Subscale</th>
<th>Adapted HIV Stigma Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Education</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Fatigue</td>
<td>$r = .478, p = .018$</td>
<td>$r = .396, p = .001$</td>
</tr>
<tr>
<td>Symptoms</td>
<td>$r = .420, p = .041$</td>
<td>$r = .481, p = .000$</td>
</tr>
<tr>
<td>Medication effects</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Positive coping</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Negative coping</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Uncertainty</td>
<td>$r = .503, p = .012$</td>
<td>$r = .335, p = .004$</td>
</tr>
<tr>
<td>Depression</td>
<td>NS</td>
<td>$r = .533, p = .007$</td>
</tr>
<tr>
<td>Fear/anxiety</td>
<td>NS</td>
<td>$r = .536, p = .031$</td>
</tr>
<tr>
<td>Social support</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Satisfaction with information (WL)</td>
<td>NS</td>
<td>$r = .656, p = .000$</td>
</tr>
<tr>
<td>Quality of Life</td>
<td></td>
<td></td>
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<tr>
<td>SF-36 physical component summary</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>SF-36 mental component summary</td>
<td>$r = -.418, p = .000$</td>
<td>NS</td>
</tr>
<tr>
<td>Social QOL</td>
<td>$r = -.459, p = .024$</td>
<td>$r = -.421, p = .000$</td>
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</table>
Table 2. Regression—Stigma Scale Scores on Predictor Variables

<table>
<thead>
<tr>
<th></th>
<th>ANOVA</th>
<th>Adjusted $R^2$</th>
<th>Significant predictors</th>
</tr>
</thead>
<tbody>
<tr>
<td>LDQOL Stigma Subscale</td>
<td>$F = 18.278$, $p = .000$</td>
<td>.271</td>
<td>Fatigue .439 5.618 .001 Age -.189 -1.993 .049</td>
</tr>
<tr>
<td>Adapted HIV Stigma Scale</td>
<td>$F = 15.922$, $p = .000$</td>
<td>.243</td>
<td>Depression .418 4.444 .000 Age -.194 -2.063 .042</td>
</tr>
</tbody>
</table>

Bivariate Analyses

In comparing the WL and PT groups, there is no difference on either of the stigma scales. Correlations within each group allowed us to examine whether the experience of stigma might be related to other biopsychosocial factors; given the distinct differences in physical and psychological functioning between the two groups (Lasker et al., 2010), we examine these separately for WL and for PT. Table 1 shows associations between stigma and other variables in our model.

While on the WL, higher scores on the LDQOL stigma scale are associated with higher levels of fatigue, symptoms, and uncertainty; results for the adapted HIV Stigma Scale are not related to biomedical factors but are related to greater uncertainty and less social support. Both are associated with less involvement in social and family life.

Post-transplant, those who rated stigma higher on both scales were younger, suffering more from medication effects and fatigue, and more uncertain and depressed, as well as lower on both the MCS and social and family involvement. Liver disease symptoms, negative coping strategies, and anxiety were associated with one of the scales PT.

Multivariate Analyses

The two stigma scales were regressed on the 12 other predictor variables in the model. Quality of Life outcome variables were excluded from this analysis because it would be conceptually invalid to examine outcomes influencing a predictor. Results of these multiple regressions are reported in Table 2 and show that the key contributors to variation in stigma are greater fatigue and younger age (LDQOL) and greater depression and younger age (adapted HIV Stigma Scale). Importantly, transplant status was not a predictor of stigma, reflecting the initial finding that scores did not differ between WL and PT groups.
Qualitative Analyses

Descriptions of stigmatizing experiences indicated that 28% involved events with health care providers, 22% involved friends, 22% strangers, 17% work-related, and the remainder did not specify the source. Notably, none involved family members. These are a sampling of the reports.

Health Care Providers

My original gastroenterologist insisted I drank like a fish even after I told him I didn't. . . . I don't think he believed me until the (PBC) diagnosis came through.
When I had high liver enzymes on a routine physical, the nurse automatically assumed that I had Hep. C and was a drug addict and asked if I had "shared needles" in a very nasty way.

Friends

Before my transplant, good friends of ours invited us to dinner at their house. After dinner we cleared the table and he rinsed dishes and put them in the dishwasher. . . . (His wife) then pulled the dishes out of the dishwasher and ran water in the sink with dish soap and Clorox.
When telling a friend about the disease she said: "what did you do that God is punishing you like this?"

Strangers

I had a waitress ask me, "My boss says you look like you're dying . . . ARE YOU!!?"
Post-transplant, when I excitedly announced that I had received the gift of life and had had a liver transplant, some people would remark that I "didn't look like a drinker" (which I am not).

Work

Because PBC had the word cirrhosis in it, parents at my school where I taught thought I was an alcoholic!
Post-transplant I have not been able to get a job and all of my former colleagues talk to me in a hushed voice as if I will fall over and die at any moment

Responses to Stigma Experiences

About one-third of participants who reported stigmatizing experiences said they were hurt by the comments, and one-third were angry. Some expressed both.
I was ashamed, and she was a nurse. She should have treated me differently.
I felt hurt and eventually distrusted my own judgment for thinking they had been better human beings than they were.
I was furious. Just recalling it makes me angry again.

A small number were accepting.

I am extremely strong and emotionally balanced and could get the support I needed from those who were close around me.
I am humbled and sorry for my past judgments on others. I now no longer judge others when they park in the handicap parking.

DISCUSSION

Stigma and PBC

Do women with PBC, a disease with non-stigmatizing etiology, experience stigma?

Direct inquiry about stigma in this study attempts to overcome an expected reluctance to discuss a sensitive topic. In a previous study analyzing posts to the PBCers online listserv, mentions of stigma were relatively rare—less than 1% of all themes (Lasker, Sogolow, & Sharim, 2005). The vast majority of communications (75%) were questions and answers about the biomedical aspects of the disease—tests, procedures, medications, etc. When people did mention stigma, it was most often in relation to the name of the illness; they found it difficult to have a disease with the word cirrhosis in it.

In the current study, stigma was explored explicitly, but it was still not the most prominent concern, and the majority disagreed with most stigma-related items. Yet 27 women either reported a stigmatizing experience or scored "high" on the stigma scales, or both. For the persons with PBC who experience stigma, there is hurt or anger. Despite their own knowledge of PBC etiology, these feelings may be due to internalizing stigma ("I was ashamed"). The issue may be not whether one experiences stigmatizing behavior, but how one copes with stigma. Does the person stay engaged or become isolated? The consequences of coping strategies may be an indicator of how important stigma is for the individual.

Of interest, many people with PBC do not "look sick"; the primary symptoms of fatigue and itching may be invisible. Typically, for others to know that someone has PBC requires disclosure. The fact that 64% agreed with the statement, "In many areas of my life, no one knows I have liver disease," indicates the lack of disclosure chosen by many women with PBC.
What factors contributed to some women experiencing more stigma?

Depression and fatigue were both found to be key correlates of stigma. These conditions are typical in PBC (Jones, 2004; Poupon, Chretien, Chazouilleres, Poupon, & Chwalow, 2004; Sogolow, Lasker & Short, 2008; van Os, van den Broek, Mulder, Borg, Brujin, & van Buuren, 2007) and may be expected to lower resistance to defending against stigma. The recipient of PBC-related stigma is more vulnerable, having reduced energy, strength, and will to respond. Other symptoms of PBC—poor concentration, disrupted sleep and appetite—can be misdiagnosed as depression, when it may be that the individual is suffering more from demoralization. Demoralization is very similar in symptomatology to depression but is not an official DSM diagnosis. It is distinguished from depression in that the symptoms would vanish if the illness could somehow be removed (Kissane, Wein, Love, Lee, Kee, & Clarke, 2004). In addition, stigma is associated in this sample with greater anxiety and fear related to the disease; such stressors may be another source of reduced energy and limited resistance to stigma.

We found that stigma is a more serious concern for younger women. This may be related to their having had less time since diagnosis, suggesting that with time some women adjusted to their condition. Yet in partial correlations, controlling for time since diagnosis, there continues to be a significant negative correlation between age and stigma ($r = -.243$, $p = .018$). One participant explained her own change with age: “These situations occurred when I was in my 40s. In later years I didn’t care and people understood.” It appears that there may be an adaptation to the situation that occurs with time and stage of life, as well as perhaps through the education of others.

Does stigma influence QOL?

Stigma was highly associated with a decreased MCS score on the SF-36 measure as well as with decreased involvement in social and family activities. It may be that when stigma is internalized, the feelings are damaging in broader ways than many people with PBC realize. Decreased involvement in social activities may be especially attractive to those who are already limited in energy or depressed. With the combination, then, of fatigue, depression, and the experience of stigma, social isolation may be multiply determined, as well as reinforcing for depression (Blackburn, Freeston, Baker, Jones, & Newton, 2007).

Measurement of Stigma

Multiple measures were used to strengthen the ability to understand stigma in this population of women with PBC. The results of this study showed that
both the LDQOL stigma scale and the adapted HIV Stigma scale are applicableor use with a population of women with PBC.

Limitations

Findings are subject to several limitations. First, for analytic purposes, it
would be helpful to have a larger sample. A larger sample of both WL and
PT participants would have increased statistical power and made it possible to
detect possible additional statistically significant results. In addition, the smaller
WL number limited the possibility of comparative analyses within that group.
Also, the sample includes only women, and it is possible that men encounter
stereotypical bias about being alcoholics or drug users as much if not more than
women. Future study would do well to examine stigma further in large, national
study samples including men with chronic liver disease. Additionally, online
recruitment, increasingly common in the study of rare diseases, has the potential
for selection bias. The similarity of online respondents in the current study to
participants recruited through medical centers is reassuring in that regard.

Second, the biopsychosocial model is conceptual and remains a guide
only. Although it was derived from the literature and is responsive to calls for
a comprehensive approach to explaining quality of life (Gutteling, de Man,
Busschbach, & Darlington, 2007), it requires further testing and refinement.

Recommendations

Participants who reported experiences with stigma most frequently cited
health care professionals as a source. Butt et al. (2008) and Moore, Hawley,
and Bradley (2008) also found health care professionals to be the most common
source of stigmatizing comments in the case of people with Hepatitis C. In
part, this may reflect the fact that persons with serious illness often interact with
health care professionals in circumstances that involve discussion of their illness.
Certainly, health care professionals need to learn more about differentiating
among the various etiologies of chronic liver disease and recognize that not all
liver disease is related to substance abuse.

This begs the issue, however, that health care professionals should not exhibit
such behavior, regardless of their personal beliefs or the cause of an illness. It
is inconsistent with the mandate to "first do no harm" and violates the norm of
professionalism. Of note, health care professionals who are stigmatizing are
a minority. Perhaps colleagues can be more proactive, reinforcing norms for
acceptable behavior and reducing the burden on their patients.

The word "cirrhosis" in the name PBC may contribute to the frequent mis-
understanding that PBC is due to alcoholism. In addition, many with PBC will
never develop cirrhosis; the name bears reconsideration for that reason alone.
We think it is important to acknowledge that public views about blaming the
victim, in this case the alcoholic or intravenous drug user, are not excusable.
Stigmatizing is an insidious kind of bullying behavior, ignoring the dynamics of addiction and accomplishing little but to hurt its target.

Regarding strategies to improve the quality of life for those with PBC, self-management programs that rely on cognitive methods have been shown in randomized clinical trials to be worthwhile (Bruce, Lorig, & Laurent, 2007; Lorig, Hurwicz, Sobel, Hobbs, & Ritter, 2004). Such programs provide counseling to address the broader issues of chronic illness and education that addresses coping strategies. Additionally, patients suffering from depression or significant anxiety symptoms should be evaluated by a mental health specialist. Thus, doctors who treat PBC patients should be aware of the prevalence of such symptoms and prepared to refer to the appropriate resources.

CONCLUSIONS

These results suggest that the people who are fragile physically, psychologically, and socially are also vulnerable to stigma. May (2006) refers to “the hard work of being ill” which involves not only coping with the physical dimensions of illness but also the interpersonal ones. People with chronic liver disease, as seen in the current study, experience this burden of physical symptoms (fatigue, medication side effects) and psychological challenges (depression, fear/anxiety, uncertainty), which are highly related to the social and psychological strains of feeling stigmatized by others. The broader issues of fatigue and depression must be addressed as aggressively as possible, and efforts to help people develop coping skills that do not involve self-blame are essential. Continuing education of health care professionals about the role of stigma in chronic liver disease and broader educational efforts to promote a reduction in stigmatizing behaviors in the public in response to diseases more generally would be very desirable.

AUTHOR BIOGRAPHIES

Dr. Ellen D. Sogolow is a social psychologist with extensive experience in public health and public policy. Formerly with U.S. Centers for Disease Control and Prevention (CDC) in Chronic Disease Prevention and Health Promotion, HIV Prevention, and Injury Prevention and Control, currently, she is a consultant with U.S. Department of Homeland Security (DHS) in the area of fire fighter and other first responder health and safety.

Dr. Judith N. Lasker is NEH Distinguished Professor and Chair of the Department of Sociology and Anthropology at Lehigh University. She is a medical sociologist with research interests in women’s health issues, illness and loss, and the relationship of community to health. She is co-author with Susan Borg of When Pregnancy Fails: Families Coping with Miscarriage, Ectopic Pregnancy, Stillbirth, and Infant Death (Bantam Books) and In Search of Parenthood: Coping with Infertility and High Tech Conception (Temple University Press).
Dr. Rebecca R. Sharim graduated from Lehigh University in 2005 with a BA in Behavioral Neuroscience. She attended Temple University School of Medicine and received her MD in 2009. She completed a year of psychiatry training and is currently in residency training in internal medicine at Temple University Hospital.

Dr. Robert M. Weinrieb is Associate Professor of Psychiatry at the University of Pennsylvania School of Medicine and Philadelphia Veterans Affairs Medical Center. He is Chief of Psychosomatic Medicine and Director of an ACGME-accredited Psychosomatic Medicine Fellowship program. He served as consultant psychiatrist for the liver transplant team of the Hospital of the University of Pennsylvania, and has researched the treatment of psychiatric and addictive disorders in organ transplant patients.

Dr. David A. Sass is Associate Professor of Medicine and Surgery at Drexel University College of Medicine and Medical Director of the Center for Hepato-biliary Disorders and Transplantation at Hahnemann University Hospital. He is also the associate chief for the Division of Gastroenterology and Hepatology. His research interests have included the genetics of autoimmune liver disease, primary biliary cirrhosis, and post-transplant osteoporosis.

(Appendices follow)
<table>
<thead>
<tr>
<th>Category</th>
<th>Measure</th>
<th>Description and maximum potential range of scores</th>
<th>Source</th>
<th>$\alpha$ (Cronbach's alpha)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>Self-report</td>
<td>Calculated from date of birth and date of survey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>Self-report</td>
<td>High school or less, some college, college graduate, post-college</td>
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<tr>
<td>Biomedical</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Transplant status</td>
<td>Self-report</td>
<td>Waiting list or post-transplant</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>Fatigue impact scale</td>
<td>40 items, 5-point scale from &quot;no problem&quot; to &quot;extreme problem&quot;; 0-160</td>
<td>Fisk et al., 1994</td>
<td>.999</td>
</tr>
<tr>
<td>Total symptoms</td>
<td>Self-report</td>
<td>8 items—ascites, bleeding problems, encephalopathy, fatigue, itching, leg swelling, osteoporosis, varices. Check those experienced in last 60 days; 0-8</td>
<td>Derived from the NIDDK-QA instrument: Friedman, Keefe, &amp; Schiff, 2004; Kim et al., 2000</td>
<td>.801</td>
</tr>
<tr>
<td>Medication effects</td>
<td>Self-report</td>
<td>17 items—agitation, anemia, difficulty concentrating, depression, diabetes, diarrhea, fatigue, headaches, insomnia, kidney disease, short- and long-term memory loss, nausea, neuropathy, osteopenia/ osteoporosis, pain, weight change. Check those experienced in last 60 days; 0-17</td>
<td>Physicians' desk reference (PDR) (2003) for side-effects of medications most commonly used pre- and post-transplant</td>
<td>.796</td>
</tr>
<tr>
<td>Psychological Coping</td>
<td>Brief COPE Scale</td>
<td>14 scales, 2 items each, indicating frequency of using different coping styles, 4-point scale from “I haven’t been doing this at all” to “I’ve been doing this a lot.” Factor analysis produced two scales:</td>
<td>Carver, 1997</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Positive coping, 10 scales, 20-80</td>
<td>.849</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Negative coping, 4 scales, 8-32</td>
<td>.726</td>
<td></td>
</tr>
<tr>
<td>Uncertainty</td>
<td>Mishel Uncertainty in Illness Scale—Adult version</td>
<td>33 items, 5-point scale, from “strongly disagree” to “strongly agree” with “undecided” mid-point; 33-165</td>
<td>Mishel, 1997</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>CES-D</td>
<td>20 items, 4-point scale from “rarely or none of the time” to “most or all of the time; 0-60</td>
<td>Radioff, 1977</td>
<td></td>
</tr>
<tr>
<td>Fear/anxiety</td>
<td>Measure created for current study</td>
<td>5 items, anxiety/fear about not obtaining a liver when needed, infection, rejection, pain, and death. 3-point scale from “very anxious/fearful,” “somewhat,” to “a little/not at all”; 5-15</td>
<td>.877</td>
<td></td>
</tr>
<tr>
<td>Category</td>
<td>Measure</td>
<td>Description and maximum potential range of scores</td>
<td>Source</td>
<td>α (Cronbach's alpha)</td>
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<td>------------------------</td>
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</tr>
<tr>
<td>Sociological Social support</td>
<td>Multidimensional scale of perceived social support</td>
<td>12 items, 7-point scale from very strongly disagree to very strongly agree with neutral mid-point; 12-84</td>
<td>Zimet, Dahlem, Zimet, &amp; Farley, 1988</td>
<td>.954</td>
</tr>
<tr>
<td>Stigma</td>
<td>LDQOL stigma subscale</td>
<td>6 items from Liver Disease Quality of Life measure, 5-point scale, from strongly disagree to strongly agree with neutral mid-point; 6-36</td>
<td>Gralnek et al., 2000</td>
<td>.878</td>
</tr>
<tr>
<td></td>
<td>Berger HIV stigma scale, adapted</td>
<td>40 items, &quot;HIV&quot; changed to &quot;liver disease&quot; and question on others' perception of substance abuse added, 4-point scale from strongly disagree to strongly agree; 40-160</td>
<td>Berger, Estwing-Ferrans, &amp; Lashley, 2001</td>
<td>.960</td>
</tr>
<tr>
<td>Information</td>
<td>Measure created for current study</td>
<td>How helpful was information received from health care personnel while on waiting list? 4-point scale from very unhelpful to very helpful; 1-4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Quality of Life
Health-related QOL
SF-36

Social QOL
Measure created for current study

36 items, 8 subscales and two summary scales**

3 items, rating of activity levels in social, work, and family life, 5-point scale from very low to very high for each domain. Asked for before illness, while on waiting list, and after transplant; 1-5 for each domain at each time.

Ware, Kosinski, & Dewey, 2000

.440
Without work: .695

*All scores are based on summing of all the individual items; the exception is the two coping measures which derived from factor analysis of the items, then the summing of scores for all items in each factor. Higher total scores always refer to a greater presence of the construct, e.g., more fatigue, more anxiety, better quality of life.

**For the purposes of the present report, we include only the analyses for the two summary scores, the Physical Component Summary and the Mental Component Summary. More detailed results are available upon request to authors. Since the scoring of the SF-36 requires several stages of transformation, we do not include the potential range of scores.
APPENDIX B: Items from the LDQOL and Adapted HIV Stigma Scales  
(Higher Scores Indicate More Agreement)

<table>
<thead>
<tr>
<th>Items</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LDQOL Stigma Scale</strong> (Gralnek et al., 2000)</td>
<td></td>
</tr>
<tr>
<td>Some people avoid me because of my liver disease.</td>
<td>1.73 (1.14)</td>
</tr>
<tr>
<td>I am embarrassed about how I look in public.</td>
<td>1.88 (1.20)</td>
</tr>
<tr>
<td>I avoid doing some things in public because of my liver disease.</td>
<td>1.91 (1.20)</td>
</tr>
<tr>
<td>Some people are uncomfortable around me because of my liver disease.</td>
<td>1.79 (1.22)</td>
</tr>
<tr>
<td>My liver disease makes me stand out in public.</td>
<td>1.55 (1.04)</td>
</tr>
<tr>
<td>Because of my liver disease, I feel flawed and incomplete.</td>
<td>1.88 (1.26)</td>
</tr>
<tr>
<td><strong>Adapted HIV stigma scale</strong> (Berger et al., 2001)</td>
<td></td>
</tr>
<tr>
<td>In many areas of my life, no one knows that I have liver disease.</td>
<td>2.77 (1.04)</td>
</tr>
<tr>
<td>I feel guilty because I have liver disease.</td>
<td>1.41 (0.74)</td>
</tr>
<tr>
<td>People’s attitudes about liver disease make me feel worse about myself.</td>
<td>1.55 (0.75)</td>
</tr>
<tr>
<td>Telling someone I have liver disease is risky.</td>
<td>1.77 (0.84)</td>
</tr>
<tr>
<td>People with liver disease lose their jobs when their employers find out.</td>
<td>1.71 (0.69)</td>
</tr>
<tr>
<td>I work hard to keep my liver disease a secret.</td>
<td>1.54 (0.78)</td>
</tr>
<tr>
<td>I feel I am not as good a person as others because I have liver disease.</td>
<td>1.30 (0.57)</td>
</tr>
<tr>
<td>I never feel ashamed of having liver disease. (reversed)</td>
<td>2.36 (1.24)</td>
</tr>
<tr>
<td>People with liver disease are treated like outcasts.</td>
<td>1.53 (0.68)</td>
</tr>
<tr>
<td>Most people believe that a person who has liver disease is dirty.</td>
<td>1.60 (0.74)</td>
</tr>
<tr>
<td>It is easier to avoid new friendships than worry about telling someone that I have liver disease.</td>
<td>1.47 (0.71)</td>
</tr>
<tr>
<td>Having liver disease makes me feel unclean.</td>
<td>1.20 (0.46)</td>
</tr>
<tr>
<td>Since learning I have liver disease, I feel set apart and isolated from the rest of the world.</td>
<td>1.64 (0.78)</td>
</tr>
<tr>
<td>Most people think that a person with liver disease is disgusting.</td>
<td>1.49 (0.65)</td>
</tr>
<tr>
<td>Having liver disease makes me feel that I’m a bad person.</td>
<td>1.20 (0.42)</td>
</tr>
<tr>
<td>Most people with liver disease are rejected when others find out.</td>
<td>1.39 (0.55)</td>
</tr>
<tr>
<td>I am very careful who I tell that I have liver disease.</td>
<td>1.80 (0.94)</td>
</tr>
<tr>
<td>Some people who know I have liver disease have grown more distant.</td>
<td>1.65 (0.85)</td>
</tr>
</tbody>
</table>
APPENDIX B: (Cont'd.)

<table>
<thead>
<tr>
<th>Items</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Since learning I have liver disease, I worry about people discriminating against me.</td>
<td>1.56 (0.72)</td>
</tr>
<tr>
<td>Most people are uncomfortable around someone with liver disease.</td>
<td>1.61 (0.70)</td>
</tr>
<tr>
<td>I never feel the need to hide the fact that I have liver disease.</td>
<td>2.23 (1.11)</td>
</tr>
<tr>
<td>(reversed)</td>
<td></td>
</tr>
<tr>
<td>I worry that people may judge me when they learn I have liver disease.</td>
<td>1.71 (0.84)</td>
</tr>
<tr>
<td>Having liver disease in my body is disgusting to me.</td>
<td>1.33 (0.52)</td>
</tr>
<tr>
<td>I have been hurt by how people reacted to learning I have liver disease.</td>
<td>1.57 (0.75)</td>
</tr>
<tr>
<td>I worry that people who know I have liver disease will tell others.</td>
<td>1.39 (0.55)</td>
</tr>
<tr>
<td>I regret having told some people that I have liver disease.</td>
<td>1.56 (0.76)</td>
</tr>
<tr>
<td>As a rule, telling others that I have liver disease has been a mistake.</td>
<td>1.42 (0.54)</td>
</tr>
<tr>
<td>People have told me that getting liver disease is what I deserve for how I lived my life.</td>
<td>1.45 (0.60)</td>
</tr>
<tr>
<td>Some people avoid touching me once they know I have liver disease.</td>
<td>1.38 (0.61)</td>
</tr>
<tr>
<td>People I care about stopped calling after learning I have liver disease.</td>
<td>1.25 (0.49)</td>
</tr>
<tr>
<td>Some people close to me are afraid others will reject them if it becomes known that I have liver disease.</td>
<td>1.23 (0.41)</td>
</tr>
<tr>
<td>People don’t want me around their children once they know I have liver disease.</td>
<td>1.28 (0.48)</td>
</tr>
<tr>
<td>People have physically backed away from me when they learn I have liver disease.</td>
<td>1.34 (0.63)</td>
</tr>
<tr>
<td>Some people act as if it’s my fault I have liver disease.</td>
<td>1.34 (0.58)</td>
</tr>
<tr>
<td>I have stopped socializing with some people because of their reactions to my having liver disease.</td>
<td>1.34 (0.58)</td>
</tr>
<tr>
<td>I have lost friends by telling them I have liver disease.</td>
<td>1.33 (0.57)</td>
</tr>
<tr>
<td>I have told people close to me to keep the fact that I have liver disease a secret.</td>
<td>1.25 (0.42)</td>
</tr>
<tr>
<td>People who know I have liver disease tend to ignore my good points.</td>
<td>1.24 (0.44)</td>
</tr>
<tr>
<td>When people learn you have liver disease they look for flaws in your character.</td>
<td>1.34 (0.57)</td>
</tr>
<tr>
<td>People who hear I have liver disease assume I am an alcoholic or drug user.</td>
<td>2.17 (0.94)</td>
</tr>
</tbody>
</table>
REFERENCES


Direct reprint requests to:

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