FOR BETTER AND FOR WORSE: FAMILY AND FRIENDS’ RESPONSES TO CHRONIC LIVER DISEASE

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ABSTRACT

Primary Biliary Cirrhosis (PBC) is a chronic and potentially fatal liver disease that primarily affects women in their middle years. Caregivers of people with PBC or other rare chronic ailments face a number of challenges; this study addresses responses to those challenges based on a survey and on messages posted to a listserv specifically for family members and friends of people who have PBC. Both revealed patterns related to life stage and gender. In general, husbands (many of them retired) reported readiness to accept changed circumstances and make behavioral adaptations, and they were unlikely to utilize online support opportunities. Female family members (many of them non-spouses) and friends were more likely to provide socio-emotional support and to use online support.

Key Words: chronic illness, caregivers, Internet support, liver disease, gender

With an aging population, chronic diseases have become more prevalent and caregiving activities more demanding. To date, little attention has been given to caregiving in relation to diseases of the liver, most of which are chronic, yet

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chronic liver disease (CLD) is the 7th leading cause of death among Americans 25-64 years old. In this study, we aimed to gain a better understanding of the impact of Primary Biliary Cirrhosis (PBC), a type of CLD that primarily affects women in their middle years, on family members and friends.

PBC is a rare autoimmune disease, thought to be related to viral and/or genetic causes (Parikh-Patel, Gold, Worship, Krivy, & Gershwin, 2001). The disabling effects of this progressive disease as well as uncertainty about outcomes create enormous challenges for the person with CLD and for his or her family and friends. In a previous study of people who have PBC and Hepatitis C (Sogolow, Lasker, Short, & Arguedas, 2002), interviews revealed the centrality of family support for people living with this chronic illness. However, many expressed concerns about being a burden on family, about not being able to provide for and help their families, and about the emotional impact of their disease on the loved ones who worry about them.

While social support is often crucial to the well-being of people with illness, the caregiving literature focuses primarily on the negative effects of providing this support on caregivers’ employment, social life, health, marital satisfaction, and general well being. The term “caregiver burden” is widely used to describe this phenomenon and is embodied in measures such as the Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) and the Care Burden Scale (Knight, Devereux, & Godfrey, 1997).

We know, however, that family systems rarely involve a one-way exchange, where gain to one person is necessarily a loss to another. Illness is one of the phenomena that can seriously disrupt an ongoing system, resulting in the necessity of regrouping and redefining relationships in ways that change everyone involved, for better and/or for worse (Biegel, Sales, & Schulz, 1991; Charmaz, 1991). Further, caregiving may have intrinsic satisfactions as well as challenges, especially when it is carried out by a loved one; and maintenance may involve positive as well as negative affect.

Studies have shown that women do the majority of the caregiving (Gerstel & Gallagher, 2001; Kuyper & Wester, 1998; Wicks, Milstead, Hathaway, & Cetingok, 1997). Even so, women generally experience more stress from caregiving than men, including guilt, strain, and the desire to give up providing care (Bookwala & Schulz, 2000; Collins & Jones, 1997; Hepburn, Lewis, Narayan, Tornatore, Bremer, & Sherman, 2002; Kirk, Barnes, & Patrick, 2002; Knight et al., 1997). The extent of gender differences in the strain of caregiving may vary by type of disease (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000).

One study, focusing on dementia, generated significant insights when husbands reported that caring gave a purpose to their lives that they would not otherwise have (Collins & Jones, 1997). This research suggests that there may be positive as well as negative effects of caregiving that should be further explored.
PBC disproportionately impacts women (90%), mostly between the ages of 40 and 60; therefore, the person most directly affected is typically a husband approaching or following retirement, or a female family member or close female friend. In this research, we explored the following questions: How do family members and friends see the illness affecting their own lives? What strategies do they use to cope? Do women and men differ in their responses?

We used a systems approach to consider families and social networks as the context in which we explored how family members and friends address their changed circumstances (Bales, 1976; Bales, Cohen, & Williamson, 1979; Reiss, Steinglass, & Howe, 1993; Walsh, 1980). This perspective makes explicit the dynamic tension that exists between getting a task achieved, on the one hand, and maintaining the system, on the other. In this instance, the task involves providing assistance and support to a family member or friend who has a chronic, progressive illness. Maintenance activities address the socio-emotional needs of the members of the family or social network to continue to function as a unit. This study of the family members and friends of people with PBC focuses on the ways in which they manage the balance among these multiple demands and how these responses differ by gender.

We also anticipated gender differences in frequency and type of communication online. Pandey, Hart, and Tiwary’s (2003) report that women are more likely to use the Internet for health information and illness-related support. Klemm, Hurst, Dearhold, and Trone’s (1999) study of cancer support groups found women more likely to communicate support and encouragement, while men were more likely to communicate information. Dickerson’s (2003) findings about Internet use in general also found women more focused on integrating Internet use with relationships and family concerns and men more on obtaining and exchanging information. Accordingly, we expect that men will post less frequently to the listserv and focus on ‘biomedical’ topics more than women.

METHOD

Permission for the study was obtained from the Institutional Review Board of Lehigh University and the Board of Directors of the PBCers Organization. This organization was started in 1996 by a few people with PBC who began corresponding by email and formed a listserv, the Daily Digest, so that others could join them. Currently over 2,400 people worldwide—persons with PBC, family members, and friends—are subscribed. The PBCers Organization sponsors a range of activities aimed at encouraging education, research, and support (http://www.pbcers.org). To address special interests of the members, separate listservs have been developed, including one for Family and Friends of people with PBC.

The data collection steps included: 1) gathering survey results from people with PBC (reported here to inform the context of caregiver responses), and
also from their family members and friends who accompanied them to a national
conference in Biloxi, Mississippi, in May 2003; and 2) coding and analyzing
posts to the “Family and Friends” listserv.

Surveys

The survey of both people with PBC and family members and friends included:
a) demographic items and b) the SF-36 Quality of Life instrument. People with
PBC also were asked if they experienced any of a list of common symptoms. We
scored SF-36 Quality of Life (QOL) data using the standard protocol (Ware,
Kosinski, & Dewey, 2000) and compared results for significant differences from
national normed data for the appropriate age group, using a Pascal program one
of the authors (LS) developed.

Family members and friends also were asked open-ended questions: “How
has your relationship with a person who has PBC affected you in your daily
life?” “What strategies have you found most helpful in coping with your role as
a support person?” Because this group came together via the Internet, we also
asked, “Have you ever gone to the Internet to learn more or get support for
PBC-related issues?” “If yes, what sites have you used?” and “What, if anything,
did you find useful about these resources?”

Using the task- and socio-emotional-orientation perspectives described above,
we coded responses to the first open-ended question (effect on daily life)
as task, (called “behavioral”) or “socio-emotional.” Based on the content of
responses, we added two other categories, “cognitive” and “no effect.” For the
second question, on strategies for coping, we classified responses in units such
as obtaining information, providing instrumental support; and accommodating,
providing emotional support.

Posts to the Family and Friends listserv

Two different time periods, Spring and Fall of 2003, were selected to avoid
possible seasonal bias. We created a codebook, expanding upon Bales’ fram-
work for classifying task- and socioemotional-orientations in an environ-
mental or organizational context as well as on our reading of the Digest and
the coding systems employed by other researchers. Bales’ framework also has
formed the basis for coding of online health-related messages by other researchers
(Bjornsdotter, 1999; Finn, 1999). The codebook for this study includes three
categories, with twelve topics in each category. The three categories are:
“Biomedical” (corresponding to task), including references to symptoms, tests,
treatments, and self-care; “Socio-emotional,” referring to emotions such as hope,
anger, and frustration, the presence or absence of support from people in their
lives, support for others on the list, and coping; and “Systems/organizations,”
including comments about the PBCer’s Organization and references to medical
care and financial issues.
Two coders independently reviewed each post, assigning codes for each coding unit, defined as a unique separate thought. A code was assigned only once in each complete message, regardless of how many times a particular topic might be expressed in that message. The coders achieved and maintained over 95% inter-rater reliability. Also, when available, we recorded demographic information about the poster, such as gender, age, and relationship to person with PBC. Data were analyzed in SPSS; tests for significant differences were used only when there were sufficient numbers in each group.

RESULTS

Survey Data on People with PBC

To understand the context of caregiver’s experience, we briefly describe the persons with PBC who attended the conference in Biloxi (N = approximately 100), of whom 87 responded to the survey. On average, the group members knew of their diagnosis for 6 years. Of the 87 respondents, 83 were women, 41% had graduated college, and 75% were over 50 years old. They reported a median number of three major symptoms, with 79.5% experiencing fatigue and 53.4% reporting pruritus (itching). Some reported potentially life-threatening symptoms of encephalopathy (inflammation of the brain causing confusion and cognitive dysfunction), 18.4%; ascites (fluid in abdomen which can become infected), 12.6%; and varices (swollen vessels in the esophagus which can rupture), 9.2%.

Of those who reported stage of illness, nearly half (44.1%) were in later stages (III or IV) of the disease. Comparing results from the SF-36 Quality of Life measure with national norms (Ware et al., 2000), those in earlier stages of the illness had significant deficits on the subscales for general health and vitality, and those in later stages had significantly poorer scores on all subscales (Sogolow, Lasker, & Short, 2005).

Survey Data on Family and Friends

Demographics

Of the approximately sixty people registered as family members or friends, 52 (86.7%) returned the survey. Of these, 34 were spouses or partners and 18 were other family members and friends. All but two spouses were male and all but two friends and other family members were female. The latter group included 3 parents, 4 children, 3 siblings, 1 other relative, and 5 friends. To avoid confounding due to gender, responses from the two female spouses and two male non-spouses were omitted.

The remaining 48 participants included 32 husbands and 16 female (non-spouse) family members and friends. Table 1 provides the characteristics of these participants. When we compared husbands with the female family and
Table 1. Selected Characteristics of Family and Friends Sample

<table>
<thead>
<tr>
<th></th>
<th>Husbands&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Female family and friends (N = 16)</th>
<th>Total&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school grad or less</td>
<td>5</td>
<td>16.1</td>
<td>2</td>
</tr>
<tr>
<td>Some college</td>
<td>10</td>
<td>32.3</td>
<td>6</td>
</tr>
<tr>
<td>College grad and post-college</td>
<td>16</td>
<td>51.6</td>
<td>8</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-40</td>
<td>2</td>
<td>6.2</td>
<td>6</td>
</tr>
<tr>
<td>41-50</td>
<td>2</td>
<td>6.3</td>
<td>3</td>
</tr>
<tr>
<td>51-60</td>
<td>12</td>
<td>37.5</td>
<td>4</td>
</tr>
<tr>
<td>61+</td>
<td>16</td>
<td>50.0</td>
<td>3</td>
</tr>
</tbody>
</table>

<sup>a</sup>One husband did not provide education response, so that for Husbands column N = 31 for education and 32 for age; for Totals column N = 47 for education and 48 for age.

friends, there was no difference in education but a significant difference in age, with husbands twice as likely to be over the age of 50 (88% compared with 44%, chi-square = 10.34, p = .001).

Quality of Life

Husbands and female family and friends scored similarly to national norms for all subscales. They were also similar to each other except for the "role-emotional" subscale, where husbands scored significantly better.

Impact on Daily Life

Nearly one-third reported that their relationship with a person with PBC had no effect on their daily lives (see Table 2). About one-third characterized the effect in behavioral terms, for instance: "I accompany her to the doctor to listen and recall conversations." "Most outdoor activities, especially morning walks, I do alone because my wife is usually not up to it." About one-fifth had a cognitive focus, for example: "I try to guess what to expect each day with respect to her mood, energy, and social needs." "I sometimes worry that this is hereditary and I may be in her shoes someday." Least mentioned were emotional effects, such as: "I have become much closer to my wife—my job is to keep her happy and content." "Relationship is getting tougher—her mood swings are greater—I find myself being mad or upset more and more." "I value time and my friend more."
Table 2. Impact of PBC: Husbands vs. Female Family and Friends

<table>
<thead>
<tr>
<th>Type of impact</th>
<th>Husbands (N = 30)</th>
<th>Female family and friends (N = 12)</th>
<th>Total (N = 42)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Behavioral</td>
<td>12</td>
<td>40.0</td>
<td>3</td>
</tr>
<tr>
<td>Cognitive</td>
<td>4</td>
<td>13.3</td>
<td>5</td>
</tr>
<tr>
<td>Emotional</td>
<td>3</td>
<td>10.0</td>
<td>2</td>
</tr>
<tr>
<td>No effect</td>
<td>11</td>
<td>36.7</td>
<td>2</td>
</tr>
</tbody>
</table>

Comparing husbands and female family and friends, the numbers are too small for findings of significant statistical differences, yet Table 2 reveals some interesting contrasts. Husbands were more likely than the female family members and friends to report that the illness had no effect on them. Further, husbands tended to emphasize behavioral effects, while female family and friends focused on cognitive effects. Both had only modest emphasis on emotional effects. Interestingly, all but one of those who said that there was no effect on their lives still cited strategies for coping with the situation.

**Strategies for Coping**

When asked, “What strategies have you found most helpful in coping with your role as a support person?” most responses were not about self care but rather about ways to address the needs of the person with PBC (see Table 3). The most frequent category of response was emotional support. Examples include: “Assure her that the household duties are not as important as her health and suggest mood elevators like visiting the grandchildren or other supportive people.” “Always telling my friend I am there for her, heart and soul.”

The second most frequent response was coded as “accommodate,” and these types of answers were found almost exclusively among husbands. They reported, for instance: “I have to be more patient and give her the time to rest.” “I have become more tuned into her issues, and accept the fact that she is limited.” Other examples of accommodation, all from husbands, emphasize the need to appear supportive: “Be supportive, or [be] quiet;” “Ignore it, other than to ask an ‘interested question’ once in a while;” “Agreeing with her.”
Table 3. Strategies for Coping with Role as Support Person

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Husbands (N = 27)</th>
<th>Female family and friends (N = 14)</th>
<th>Total (N = 41)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Listen</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obtain information</td>
<td>0</td>
<td>0.0%</td>
<td>5</td>
</tr>
<tr>
<td>Accommodate</td>
<td>11</td>
<td>40.7%</td>
<td>1</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>8</td>
<td>29.6%</td>
<td>3</td>
</tr>
<tr>
<td>Emotional support</td>
<td>10</td>
<td>37.0%</td>
<td>5</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>3.7%</td>
<td>0</td>
</tr>
</tbody>
</table>

*Percentages add to more than 100 due to multiple answers—11 people gave two types of answers, and two gave three types of answers.

Two of the husbands objected to the phrasing of the question. One wrote, "I never thought of it as a strategy, just to be there and be supportive." The other wrote, "I do not believe I have needed strategies to help me cope as a support person."

On the other hand, female family and friends' responses were most typically coded as "listening". For example, one woman wrote: "Listening skills are important. Ask questions like 'How are you feeling this week?' Actually listen to the answer."

Relatively fewer efforts focused on the strategies coded as "obtain information" and "instrumental support." Some husbands, however, emphasized instrumental support by noting a new orientation to helping at home and pride in new skills acquired. For example, one man listed many household chores he does now, such as ironing and dishwashing, which he "never thought possible." Another wrote, "As a caregiver, I realize I can do 2½ tons more than I ever thought possible and still continue to be employed." Some female family and friends, on the other hand, became involved with obtaining information as a way of coping. "Being informed about the disease empowers me."

Use of the Internet

About half (54.5%) said they had gone to the Internet to learn more or get support for PBC-related issues. Fifteen (51.7%) of the husbands used Web
resources, compared to nine (60.0%) of the female family and friends. The PBCers.org site was by far the most frequently mentioned ($n = 13$), followed by the American Liver Foundation ($n = 4$) and Google for searching ($n = 4$). When asked what they find useful about the sites that they visit, respondents focused primarily on the search for specific biomedical information, e.g., on symptoms and medication; several referred to the value of the PBCer's site for support as well as information.

*Posts by Family Members and Friends*

**Demographics**—Over the course of two months in the spring and fall of 2003, there were 23 posters, and gender could be determined for 22. Six (27.3%) were males (4 husbands, 1 brother, and 1 who did not indicate relationship), and 16 (72.7%) were females (6 daughters—one of whom has PBC herself, 3 wives, 3 sisters, 2 women who themselves have CLD—inconsistent with the purpose of the listserv, 1 daughter-in-law, and 1 granddaughter). No one identified as a friend, although the listserv aimed to include friends.

**Message content**—The 23 people posted 92 times, with an average of 4 posts per person. Frequency per person varied greatly, from one to 18 posts per person. Three women accounted for half of all posts. Overall, 84.6% of posts were from women and 15.4% from men.

The number of topics per post ranged from 1–30 out of a total potential 36; the mean number per post is 8.8. For the 92 posts, we found 76.1% addressed at least one topic in the biomedical category, 96.7% included a socio-emotional topic, and 62.0% referred to organizational/systems topics (not mutually exclusive) (see Table 4). Of the 8.8 average topics per post, an average of 3.0 were biomedical, 4.6 were socio-emotional, and 1.2 were organization/systems topics.

There was no difference between men and women in the number or content of topics included in their posts; women's posts contained a mean of 8.97 topics each, and men's contained 8.21 each. The topics were also comparably distributed among the biomedical, socio-emotional and organization/system categories.

Six topics were utilized in more than 45% of all posts: peer support (80.4%), negative emotions (71.7%), positive emotions (69.6%), relationships with family and friends (54.3%), PBCers Organization (47.7%), and coping strategies (46.7%). Of note, five of these six topics were classified as socio-emotional. Overall, these posts reflected the frustrations, grief, and worries of the posters and the sympathetic responses they received from each other. We present here examples from these six topics. (Note: To present meaningful examples, we provided quotes longer than the coding unit—the single thought, sometimes meaning that multiple topics are included.)
Table 4. Number and Percent of Posts that Include the Category/Topic  
(N = 92 Posts)

<table>
<thead>
<tr>
<th>Category/Topic</th>
<th>N of posts</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biomedical (Mean 3.0 topics per post)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver disease</td>
<td>32</td>
<td>34.8</td>
</tr>
<tr>
<td>Diagnosis/prognosis</td>
<td>31</td>
<td>33.7</td>
</tr>
<tr>
<td>Symptoms</td>
<td>38</td>
<td>41.3</td>
</tr>
<tr>
<td>Medications</td>
<td>28</td>
<td>30.4</td>
</tr>
<tr>
<td>Health care provider</td>
<td>29</td>
<td>31.5</td>
</tr>
<tr>
<td>Tests/procedures</td>
<td>33</td>
<td>35.9</td>
</tr>
<tr>
<td>Self-care behaviors</td>
<td>6</td>
<td>6.5</td>
</tr>
<tr>
<td>Other non-liver diseases</td>
<td>32</td>
<td>34.8</td>
</tr>
<tr>
<td>Transplant</td>
<td>24</td>
<td>26.1</td>
</tr>
<tr>
<td>Research</td>
<td>5</td>
<td>5.4</td>
</tr>
<tr>
<td>Other biomedical</td>
<td>7</td>
<td>7.6</td>
</tr>
<tr>
<td>Seeking biomedical information</td>
<td>15</td>
<td>16.3</td>
</tr>
<tr>
<td>Socioemotional (Mean 4.8 topics per post)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual/prayer</td>
<td>22</td>
<td>23.9</td>
</tr>
<tr>
<td>Negative emotions</td>
<td>66</td>
<td>71.7</td>
</tr>
<tr>
<td>Positive emotions</td>
<td>64</td>
<td>69.6</td>
</tr>
<tr>
<td>Thoughts about the future</td>
<td>28</td>
<td>30.4</td>
</tr>
<tr>
<td>Relationship to health care provider</td>
<td>13</td>
<td>14.1</td>
</tr>
<tr>
<td>Role change/identity</td>
<td>28</td>
<td>30.4</td>
</tr>
<tr>
<td>Stigma</td>
<td>3</td>
<td>3.3</td>
</tr>
<tr>
<td>Relationships with family and friends</td>
<td>50</td>
<td>54.3</td>
</tr>
<tr>
<td>Peer support (i.e., others on the list)</td>
<td>74</td>
<td>80.4</td>
</tr>
<tr>
<td>Coping strategies</td>
<td>43</td>
<td>46.7</td>
</tr>
<tr>
<td>Other socio-emotional</td>
<td>15</td>
<td>16.3</td>
</tr>
<tr>
<td>Seeking socioemotional response</td>
<td>14</td>
<td>15.2</td>
</tr>
<tr>
<td>Organizational/Systems (Mean 1.2 topics)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PBCers Organization (including internet site)</td>
<td>44</td>
<td>47.7</td>
</tr>
<tr>
<td>PBCers/ALF fund-raising</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Local PBCers activities</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Hospitals/treatment organizations</td>
<td>14</td>
<td>15.2</td>
</tr>
<tr>
<td>Health care providers in general</td>
<td>17</td>
<td>18.5</td>
</tr>
<tr>
<td>Medical insurance</td>
<td>4</td>
<td>4.3</td>
</tr>
<tr>
<td>Social Security/disability insurance</td>
<td>3</td>
<td>3.3</td>
</tr>
<tr>
<td>Pharmaceuticals</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Financial issues</td>
<td>8</td>
<td>8.7</td>
</tr>
<tr>
<td>Employment issues</td>
<td>4</td>
<td>4.3</td>
</tr>
<tr>
<td>Other organizational/systems</td>
<td>9</td>
<td>9.8</td>
</tr>
<tr>
<td>Seeking organizational/systems response</td>
<td>4</td>
<td>4.3</td>
</tr>
</tbody>
</table>

*Indicates that 34.8% of all posts included a comment about liver disease.
Peer support

 Daughter of a person with PBC—[Name], thank you so much for your post—and please please please don’t ever worry about what you say in here. . . . We are your shoulders. I’m just truly so glad that you felt you could honestly say how you were feeling right then.

Negative Emotions

 Husband—Things get pretty tough between us sometimes and I’m not sure what I can do to help. . . . Our local doctor told us that there was nothing that he could do but sit back and watch her die, I cannot accept this, there’s got to be something. . . . I do apologize for getting angry, and for carrying on.

Positive Emotions

 Daughter-in-law—I actually slept last night for the first time in months. This morning the sun is out, and the birds are chirping. I’m enjoying my cup of coffee, something I love. . . . I definitely have renewed strength from being able to share my story with all of you.

Relationships with Family and Friends

 Daughter—I took care of my PBCer [relative] in our home, for many years. No matter how much help and love I got from extended family, I found that they were usually not the people I could really say things to, because they would react so strongly.

PBCers Organization

 Wife—This group is so understanding and compassionate. It is not just the information that we get here that helps us all deal with what is sometimes hard, but the love that is shared—the kind of special love one has for other people facing difficult times.

Coping Strategies

 Granddaughter—I have given this a lot of thought and I always come back to the Serenity Prayer. I cannot change her; I can only change my responses to her.

DISCUSSION

This study of family and friends’ responses to Chronic Liver Disease has several limitations. The first is that we used convenience samples that are not representative of the universe of those with PBC or their family and friends. As a result, at least three biases may be considered. One is that the people with
PBC might be healthier than their peers who did not travel to a conference. Although the Quality of Life results indicate that the conference attendees are on the whole significantly less healthy than national norms, surely those who were severely ill were probably absent. Second, the family members and friends we surveyed might be more involved and committed than others not attending a conference. Third, those with the education and resources to be involved with online activities and to attend a conference are probably not representative. Recognizing these biases does not make answers to the research questions more predictable. Nevertheless, it will be important to seek out others who are less readily accessible to have a more complete view.

Secondly, it is possible that some men are disinclined to articulate their concerns and feelings, at least in an open forum such as the listserv or even in the context of a written survey that did not require names. Findings of minimal impact, therefore, may require more in-depth investigation with other methods such as interviews.

Third, we do not have information from the family members and friends regarding the illness status of their loved one. Yet we know that severity of illness is a major predictor of the strain experienced by caregivers (Biegel et al., 1991). Further studies with regard to the impact of chronic liver disease should include a measure of severity.

**Themes**

There were many themes in these findings. Some of the most important are:

*For better and for worse*—Some husbands explicitly linked their current situation to their wedding, when they vowed “for better or for worse.” One wrote, “I always remember I married her for who she is, not what she can do.” Another responded, “I am very fortunate that I love my bride today as I did so many years ago.” The implication of such comments is that they take it as their role to accept and make the best of the current circumstances of their spouses’ PBC.

Some family members and friends emphasized “for better.” They stated that facing mortality deepened their appreciation of their loved ones. Comments pointed to enduring love and valued friendship. From this perspective, some caregivers experience illness in their family or social network as including a strong positive aspect. On the other hand, some emphasized “for worse.” These caregivers described the pain of seeing their loved ones suffer, and their frustrations with trying to adapt to changing moods and physical limitations.

*Adaptation*—Many described changes made to adapt to the demands of PBC in their lives, such as added tasks at home and efforts to give extra attention and sympathy. At the same time, they reported that these changes were now part of everyday life; adaptations that began with diagnosis many years
earlier had become routine. As one husband reported when asked about strategies for coping: "A little understanding in the beginning stages settles into normalcy after a while."

*Life stage*—This is a population of mostly middle- and older-aged people, and many have already developed strong problem-solving skills and coping strategies based on handling previous stressful life events. Some husbands mentioned that since they are retired, they have the time to make any needed adjustments. One reported:

> As a recent retiree, I have spent much more time with my spouse than [I did] while working. The increased time we now spend together has created additional adjustments and attitude changes to remind myself to be more aware and more understanding of what my wife goes through each day as she carries out her daily routine.

*Task and socio-emotional orientations*—When asked about the impact of the illness, husbands tended to be matter-of-fact and more oriented to actions. For some, this meant taking on more household duties, for others it meant doing more outside the home and on their own. Women family members and friends tended to focus more on the socio-emotional aspects of their relationship, both in their responses to the survey and in their dominance of the listserv discussions. It may be that friends and non-spouse relatives, usually not living with the person who has PBC, have less need for attention to daily household and other functional challenges. Perhaps, being one step removed, they can also allow more emotionality in their daily life with less fear of being overwhelmed by it.

*PBCers Organization as a source of support*—PBCers Organization is a highly-valued resource. The PBCers.org internet site—including its PBCers Digest, listservs, chat rooms, and other informational resources—provides a tremendous amount of information and support. Almost half of posts to the Family and Friends listserv mentioned the PBCers Organization, usually the listserv specifically, referring to the help it provides. The availability of a listserv specifically for family members and friends is a valuable aspect of the PBCers Organization, although it is used for posting on a regular basis by a relatively small number of people. Its value is particularly great because PBC is a rare disease, and the lack of others in the local community with the same illness is an intrinsic barrier to obtaining information and support.

The PBCers Organization may also contribute indirectly to family members and friends in another way. Call, Finch, Huch, and Kane (1999) found that social isolation of the ill person intensified the burden on the caregiver, especially spouses. The availability to people with PBC of a supportive network of peers likely contributes to reducing stresses on family members and friends.
Contributions of the Findings

Online support for family members and friends—The proliferation and importance of Internet-based support has been increasingly the subject of social science and health education research (LaCoursiere, 2001; White & Dorman, 2001). Yet the subject of online support for family members and friends affected by illness has only rarely been studied in the growing literature on Internet-based support (for exceptions, see Baum, 2002; Perron, 2002; Steiner & Pierce, 2002). The PBCers Organization’s involvement of significant others in its biannual conference and in a listserv provided for their specialized needs offers a model of a consumer-generated network of support. The involvement of family members and friends in other disease-related online support networks deserves more attention in the research on the impact of caregiving.

Gender and online communication—Consistent with Pandey et al.’s (2003) observation that women are more likely to use the Internet for health information and illness-related support, we found an over-representation of female family members both in terms of who posts to the Family and Friends listserv and the number of posts per person. However, in terms of content of online communication, our results depart from earlier studies of gender differences (Dickerson, 2003; Klemm et al., 1999) that found that women were more likely to communicate support and encouragement, while men were more likely to communicate information. Recognizing that the number of men was small, we found no difference between men and women with regard to the mean number of Biomedical, Socio-emotional, and Systems topics addressed in their posts. The men who post online do not appear to be significantly different from the women in the nature of their concerns; the difference is in their being less likely to post at all.

This phenomenon may arise in part from the link between the Family and Friends listserv and the Daily Digest, which is designed primarily for people who have PBC and has a strong informational emphasis. A separate analysis of Digest postings during the same time period as the Family and Friends data reported here (Lasker, Sogolow, & Sharim, 2005) found that, in contrast to Family and Friends, topics in the Biomedical category are by far the most frequently included in messages. Messages are also considerably briefer than those on the Family and Friends listserv, with half the number of topics per post. For this population, different online norms for the two lists may be as predictive as gender.

Gender and caregiving—This study, similar to others comparing men and women caregivers, found evidence of greater focus on the emotional impact of the illness on the part of the women. Husbands were considerably less likely to report on the many potential difficulties inherent in living with a person who has a serious chronic illness.
There are a number of possible explanations for this phenomenon. One is the common belief that women are better suited to caregiving (Collins & Jones, 1997); because caregiving is not an expected role for men, they are likely to receive more gratitude from their wives, more recognition from others, and more offers of help, particularly from other female relatives (Allen, 1994). This last phenomenon is reflected in the greater presence of non-spouse caregivers among women at the conference and also on-line.

Men appear to gain more than appreciation for their caregiving. As suggested by Collins and Jones (1997), caring for their wives may provide a greater sense of purpose to their lives. This may be particularly true for men in retirement, a time often characterized by role loss for men (Wan & Odell, 1983). This is supported by our findings on expressions of pride in acquisition of new practical and communication skills on the part of many husbands.

Another possible explanation derives from social scientists’ analysis of the role of exchange and reciprocity in relationships (Homans, 1958; Mauss, 1967). Call et al. (1999) use exchange theory to argue that caregivers’ perception of the burden of caregiving should be understood within the context of social exchanges in their relationship to the ill person over the long term. This leads us to suggest, along with Biegel et al. (1991) that husbands who report minimal burden may be practicing a form of delayed reciprocity—they may see it as their turn to take care of the women who had taken care of them and their families for many years. Future research could address this aspect of caregiving.

CONCLUSIONS

Recent years have seen increased attention to the experiences of men who are caregivers (Gerstel & Gallagher, 2001; Kramer, 2002; Kramer & Lambert, 1999). Our findings, based on two sets of data on family members and friends of people with chronic liver disease—one from a national conference and the other from an online support network—suggest that men may not be seeking much support from others in their same situation. While those who attended the conference did have opportunities for mutual support, including in organized sessions that were open only to family members and friends, very few of them are looking to the unique opportunity offered by the Family and Friends listserv for advice or assistance.

The findings suggest that the husbands in this study have mostly found ways to adapt to the new situation, despite frustrations arising for some of them from their wives’ physical and emotional changes. The availability of female family members and friends who are involved in supporting the person with PBC, as well as the emotional support available from others in the organization, also appear to be very important. It would be valuable to seek out family members and friends who are not as well connected to the PBCers Organization for comparison.
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REFERENCES

Baum, L. S. (2002). Factors related to use of Internet parent support groups by primary caregivers of a child with special health needs. Dissertation Abstracts International: Section B: The Sciences and Engineering, 63(2B), 734.


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