More Americans try to change their health behaviors through self-help than through all other forms of professionally designed programs. Mutual support groups, involving little or no cost to participants, have a powerful effect on mental and physical health, yet little is known about patterns of support group participation in health care. What kinds of illness experiences prompt patients to seek each other's company? In an effort to observe social comparison processes with real-world relevance, support group participation was measured for 20 disease categories in 4 metropolitan areas (New York, Chicago, Los Angeles, and Dallas) and on 2 online forums. Support seeking was highest for diseases viewed as stigmatizing (e.g., AIDS, alcoholism, breast and prostate cancer) and was lowest for less embarrassing but equally devastating disorders, such as heart disease. The authors discuss implications for social comparison theory and its applications in health care.

The experience of illness is a profoundly social one. Suffering elicits intense emotions and hence the desire to talk to others. Through interpersonal exchanges, patients develop an understanding of their illness: They may talk to friends, relatives, and professionals about their diagnosis and treatment may entail. Over the course of their particular illness, relationships are strained or broken, and new ones become valuable, such as those with doctors, nurses, or physical therapists. For some, the condition itself constitutes a dangerous secret that erects a barrier between themselves and their support network. Thus, patients' experiences of illness both influence, and are influenced by, the social fabric that surrounds them.

A recent development in the social milieu of the patient is the proliferation of mutual support groups for people coping with illness. Across the country, in hospitals, churches, empty offices, and even shopping malls, small groups of individuals assemble to cope collectively with their unique challenges. Such populist approaches often go unnoticed by psychologists because of a bias toward professionalism on the one hand and a lack of awareness on the part of group participants that they are part of a larger movement on the other (Jakobs & Goodman, 1989). The psychological and physical health importance of this diffuse community is striking. Through such groups, millions of Americans attempt to overcome addiction, discuss innovations in insulin treatments, grieve for the loss of a breast, or share fears about the possible progression of HIV to AIDS. Some conditions are associated with more support groups than others. What kinds of illness experiences prompt the formation and maintenance of support groups? What makes the support group appealing for cancer patients but not for cardiac patients? Why is mutual support an intrinsic part of AIDS case management but utterly lacking from hypertension treatment?

**Venues for Social Comparison**

Festinger's (1954) social comparison theory postulated that social behaviors could be predicted largely on the basis of the assumption that individuals seek to have and maintain a sense of normalcy and accuracy about their world. In times of uncertainty, Festinger predicted that affiliative behaviors would increase as people sought others' opinions about how they should be thinking or feeling.

Empirical tests of social comparison theory have found that affiliative behaviors increase under conditions of high anxiety. Participants awaiting a false medical procedure presumed to include an electric shock expressed a strong preference for the presence of another, especially someone facing the same procedure (Schachter, 1959). However, later studies about affiliative motivation raised further doubts about social comparison motives (e.g., Teichman, 1973). Saroff and Zimbardo (1961) examined preferences of college students who thought they were awaiting an electric shock but also were told that they would be required to suck bottle nipples as part of the experimental procedure. In this more embarrassing context of anxiety, participants indicated a marked decrease in the desire to have another present. Saroff and Zimbardo concluded that the kind of anxiety associated with humiliation...
or embarrassment actually would decrease affiliative motivation. Anxiety apparently motivated socialization but could not serve as a singular explanatory variable in the social comparison process, because the emotion resulted from different concerns.

Social comparison is intrinsic to the health care setting, where anxiety levels are often high, and information, when available, may not come in a form that patients understand. Diagnosis, treatment, side effects of medication, or other kinds of life disruptions prompt patients to talk with others undergoing a similar challenge.

**Characterizing the Self-Help Category**

The self-help concept stems from the assertion that people facing a similar challenge can help each other simply by coming together. The power of this approach lies in the belief that a collective wisdom is born through the shared experience of participants rather than through the professional training or style of the leader. The kinds of help requested and offered in this context are largely free of professional structures or assumptions (Riessman, 1985). Self-help group participation costs its members little or nothing.

Overall epidemiological figures on self-help in the United States indicate a prevalence rate of approximately 3% to 4% of the population over a 1-year period, and lifetime participation rates are estimated at around 25 million (Kessler, Mickelson, & Zhao, 1997; Lieberman & Snowden, 1993). Lifetime use of self-help is higher for men than for women (3.6% vs. 2.4%). Caucasians are three times as likely to participate as African Americans, with Hispanic participation levels falling about midway between the two. The mean age of participants is 43.1 years, and mean education level is 12 years (slightly higher than the national average of 11 years).

Due to the grass-roots nature of the self-help phenomenon, support groups exist in a wide range of styles and structures. Precise boundaries around self-help categorization are not only difficult, but impractical. Within the self-help arena, considerable innovation and diversity of style occur as participants tailor group processes over time to reflect group needs and goals. Lieberman and Snowden (1993) have reported that over 60% of observed groups were professionally facilitated while simultaneously being characterized as self-help. Such findings point to the difficulty of categorizing boundaries and the problematic nature of research in real-world social patterns. Nevertheless, groups that define themselves as self-help, whether they are professionally led or not, are viewed by members as self-help. For example, many hospital-based support programs described as professionally facilitated are in fact hybrid programs developed with guidelines from a national foundation and idiosyncratically shaped by the time commitments of the patient volunteers and the coordination skills of a nurse or social worker employed by the hospital.

Group counts say little about health outcomes or other quality-of-treatment measures, just as other reports of social participation, such as church membership or marital status, say little about the quality of those experiences. Although distinctions between professionally facilitated and peer-mediated groups may be meaningful in outcome studies aimed at discerning the active agents in curative processes, it is important to bear in mind that as a measure of basic value to participants, participation is its own index of success: Groups without value cease to be groups. Members vote with their feet.

The most comprehensive analysis of self-help groups in general found that the leading reason for participation in groups of any kind was the experience of physical illness (Lieberman & Snowden, 1993). Even after excluding coping with substance abuse, groups for coping with physical illness composed approximately 42% of the self-help group population, dwarfing statistics for bereavement, crime victimization, parenting issues, and personal growth, yet no studies have addressed the epidemiology of mutual support by diagnostic category.

**Effectiveness of Mutual Support in Improving Physical and Psychological Health**

Support groups are an important means by which Americans change their health behaviors. In some cases, mutual support constitutes the exclusive “treatment” for a health problem, as in the case of Alcoholics Anonymous (AA). Self-help has also been found to be as effective as professional treatment for some forms of mental (e.g., depression) or physical (e.g., headache) illnesses that have traditionally been viewed as the domain of psychotherapy or medicine (Gould & Clum, 1993). The stories told and heard in this context carry the weight of shared experience, the emotional potency of common suffering, and an avenue for social learning. Rappaport (1993) has suggested that these shared stories form a kind of group narrative that constitutes a social identity, distinguishing the self-help group from any kind of formal psychotherapy (see also Gergen & Gergen, 1997). In a similar vein, Yalom (1995) has asserted that self-help groups offer a unique venue for growth, social experimentation, and change.

Measurement of the efficacy of self-help is problematic from the outset because of its inherently self-selected nature. However, investigations of the effects of support-group participation, even under random assignment, have yielded positive results on the whole. Rheumatoid arthritis, cancer, heart attack, and epilepsy patients in support groups, for example, have exhibited more health benefits than nonparticipating controls or controls on a waiting list (Bradley et al., 1987; Dracup, 1985; Droge, Arntson, & Norton, 1986; Telch & Telch, 1986). Mutual support interventions can be highly cost effective: One study of rheumatoid arthritis patients participating in peer-facilitated groups reported mean pain reductions of 20%, increases in self-efficacy, and an average four-year cost savings of $648 per person (Lorig, Mazsonson, & Holman, 1993). Pain reductions were strongly related to increases in self-efficacy, an identified factor in positive health behavior change (DiClemente, 1995). If typical self-help participation rates (3%) occurred among the 32 million arthritis sufferers, the four-year savings in arthritis care alone could
total $650 million. The pressures of managed care and incentive structures such as capitation may increase attention to lower cost approaches to health management.

Support group participation has also been associated with superior prognosis in breast cancer and heart disease. In one highly publicized study, a sample of 88 metastatic breast cancer patients received either group psychotherapy or informational and nutritional support. Those randomly assigned to the therapy condition had survival times approximately twice those of controls (1.50 vs. 0.75 years, respectively; Spiegel, Bloom, Kraemer, & Gottheil, 1989). Similar findings have been reported for a sample of patients with malignant melanoma (Fawzy et al., 1993). Finally, various programs have been adopted for heart patients that have relied heavily on regular group support for patients and, on occasion, their spouses. Across multiple studies, markers of heart disease progression, including measures of atherosclerosis and resting blood pressure, have demonstrated clinically significant improvement (Ornish et al., 1990).

The interventions cited above represent highly refined, professionally developed, programmatic approaches to coping with serious health threats. Although they bear marked differences from patient-initiated groups, they may also share some fundamental therapeutic qualities worth noting, such as opportunities for disclosure, empathic connection, shared goals, and psychological adjustments to life challenges. They underscore the medical value of meaningful, group-based programs whose psychological focus elicits psychosocial and physical health benefits. Additional research can help clinicians identify the optimal blend of patient and professional agendas to maximize treatment success.

On the basis of these very limited reports, it is apparent that group approaches to health care can play an instrumental role in health behavior change, treatment adherence, cost control, and disease reversal. Such groups have significant therapeutic potential, yet it is apparent that the primary feature of mutual-support participants is their self-selected nature. These considerations prompted a series of investigations about the demand side of the support group community—who participates and why.

Examining Supportive Behaviors as a Function of Illness Type

Illnesses vary along a number of psychologically meaningful dimensions, such as life threat, embarrassment, and behavioral impact on disease course. Although health concerns are the most frequently cited reason for joining a support group, no studies have examined how support-group participation varies as a function of illness features or type. We designed a series of three studies to assess (a) the prevalence of support groups in 20 different patient populations, (b) the activity rates of virtual support forums for those same patient groups, and (c) the identifiable factors associated with support seeking across diagnostic category.

Our choice of methodology merits some discussion. The selection of diseases, rather than individuals, as sub-

Study 1: Assessing Support Patterns in Metropolitan Areas

Four major metropolitan areas—Chicago, Dallas, Los Angeles, and New York—were the focus of a semistructured series of surveys to identify the number of support groups in that area for patients suffering from 20 different health problems. We contacted the mental health services agency serving each of the surveyed cities and requested any handbook or comprehensive compilation of support groups for that area. After receiving the compilations, each agency or contact listed under every diagnostic category studied was called to confirm that the group existed and was not a duplicate or expired listing. Counts resulting from these calls were assembled into a support profile for each city.

Disease Selection Criteria

The conditions selected for study are listed in Table 1. The selection process was driven by practical rather than theoretical reasons, with the goal of capturing a wide range of problems that afflict people potentially capable of attending a support group. Inclusion efforts focused on the most prevalent and deadly conditions, as well as those with significant psychological and behavioral components, pre-
Table 1
An Overview of the Prevalence and Death Toll Associated With the Studied Diseases

<table>
<thead>
<tr>
<th>Disease type</th>
<th>Prevalence</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rate (in thousands)</td>
<td>Rank</td>
</tr>
<tr>
<td>AIDS</td>
<td>785</td>
<td>16</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>13,760</td>
<td>5</td>
</tr>
<tr>
<td>Anorexia nervosa</td>
<td>530</td>
<td>18</td>
</tr>
<tr>
<td>Arthritis</td>
<td>32,642</td>
<td>1</td>
</tr>
<tr>
<td>Asthma</td>
<td>13,074</td>
<td>6</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>1,769</td>
<td>13</td>
</tr>
<tr>
<td>Colon cancer</td>
<td>911</td>
<td>15</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>394</td>
<td>19</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>583</td>
<td>17</td>
</tr>
<tr>
<td>Chronic fatigue</td>
<td>1,000</td>
<td>14</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>30,000</td>
<td>2</td>
</tr>
<tr>
<td>Depression</td>
<td>9,400</td>
<td>8</td>
</tr>
<tr>
<td>Diabetes</td>
<td>7,813</td>
<td>9</td>
</tr>
<tr>
<td>Emphysema</td>
<td>1,900</td>
<td>12</td>
</tr>
<tr>
<td>Heart disease a</td>
<td>21,255</td>
<td>3</td>
</tr>
<tr>
<td>Hyperextension</td>
<td>27,549</td>
<td>3</td>
</tr>
<tr>
<td>Migraine</td>
<td>11,023</td>
<td>7</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>350</td>
<td>20</td>
</tr>
<tr>
<td>Stroke</td>
<td>3,000</td>
<td>11</td>
</tr>
<tr>
<td>Ulcer</td>
<td>4,569</td>
<td>10</td>
</tr>
</tbody>
</table>


1 The prevalence rate for heart disease is the sum of 12,490,000 myocardial infarction and coronary heart disease diagnoses and almost 8,000,000 angina cases with or without identified heart problems.

2 For the four surveyed areas, the handbooks used were as follows: Los Angeles—Los Angeles County Social Service Resource Directory; New York—Social Service Directory of Greater New York City and Directory of Self-Help Groups in New York City; Chicago—Directory of Self-Help and Mutual Aid Groups; Dallas—united private compilation provided by the Dallas County Mental Health Association. All listings under the relevant category were taken unless there were more than 20 separate listings, in which case only the first 20 were contacted, and the mean results of those first 20 were extrapolated to the rest of the listings. For example, more than 20 agencies and individuals facilitate groups for AIDS patients in the New York area, so the first 20 listed were contacted. The number of groups in existence was obtained for each listing, and then these numbers were averaged; the resulting average was multiplied by the total number of listings.

3 When no group was called but there was no answer, there were three possible outcomes: (a) If a message machine played a tape of scheduled meetings, that information was regarded as current confirmation and was recorded as data. (b) If a message machine identified that listing (telephone number) as the contact for a support group, the researcher would record the group as "1" and make an effort to call back and confirm. (c) If a message machine answered and no mention was made of a group, or in the case of no answer at all, the researcher made three further attempts to confirm the listing. No groups were counted unless confirmed. Finally, if in the course of the survey the contact person volunteered the name of a group or agency that was not featured in the researcher's registry, the researcher also contacted that group.

Survey Procedure

The goal of the research was to identify as many groups as possible per condition in a way that minimized sampling bias and reflected the approach of potential users. For this study, a group was counted as self-help if the cost of participation did not exceed $6 per session, if the respondent depicted the group as self-help, and if the meetings were held on a regular basis, whether the group was professionally facilitated or not.

We identified and contacted groups for confirmation through the listings in local registries of self-help and social service facilities. These registries feature listing categories according to diagnosis or need, such as "bereavement" or "diabetes." Once the groups were identified, we contacted each one and, in a standardized protocol, determined the number of groups run through the particular agency, the frequency of group meetings, and the average group size.

Survey Results and Discussion

The survey process yielded a total of 12,596 support groups in the four cities. The raw counts, the population-adjusted counts, and the prevalence-adjusted indices of support offer a variety of insights about the scope and frequency of support seeking for mental health challenges (see Table 2).

As is evident at the bottom of Table 2, the four cities varied considerably in the tendency to participate in support groups. Population-adjusted group totals indicate that some cities are characterized by higher overall support levels than others. A chi-square analysis of the four city group totals (adjusted) yielded a highly significant difference between expected and observed totals for the four cities. $\chi^2 (3) = 491.31, p < .001$. Dallas had the lowest level of support, with 139.5 groups per million, whereas Chicago had the highest mean of 754.9. Although it is beyond the scope of this study to identify the reasons for these variations in support levels across cities, it would be helpful to understand the factors at work—local mental health appropriateness levels, foundation support, population density, or historical and cultural orientations—that

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Table 2
Support Group Totals by Condition and City, Mean Groups Across Cities, and Prevalence-Adjusted Support Indices Across Cities, Along With Their Ranks

<table>
<thead>
<tr>
<th>Condition</th>
<th>Chicago</th>
<th>Dallas</th>
<th>Los Angeles</th>
<th>New York City</th>
<th>All cities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. of groups</td>
<td>Rank</td>
<td>No. of groups</td>
<td>Rank</td>
<td>No. of groups</td>
</tr>
<tr>
<td>AIDS</td>
<td>21</td>
<td>9</td>
<td>35</td>
<td>2</td>
<td>1,55</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>4,003</td>
<td>1</td>
<td>128</td>
<td>1</td>
<td>2,835</td>
</tr>
<tr>
<td>Anorexia</td>
<td>32</td>
<td>8</td>
<td>2</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Arthritis</td>
<td>19</td>
<td>11</td>
<td>5</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>Asthma</td>
<td>19</td>
<td>11</td>
<td>22</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Cancer, breast</td>
<td>57</td>
<td>4</td>
<td>12</td>
<td>4</td>
<td>18</td>
</tr>
<tr>
<td>Cancer, colon</td>
<td>37</td>
<td>5</td>
<td>2</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>Cancer, lung</td>
<td>1</td>
<td>16</td>
<td>2</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>Cancer, prostate</td>
<td>13</td>
<td>13</td>
<td>6</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>Chronic fatigue syndrome</td>
<td>19</td>
<td>11</td>
<td>1</td>
<td>15</td>
<td>1</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>2</td>
<td>15</td>
<td>0</td>
<td>18</td>
<td>0</td>
</tr>
<tr>
<td>Depression</td>
<td>57</td>
<td>3</td>
<td>6</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Diabetes</td>
<td>88</td>
<td>2</td>
<td>1</td>
<td>15</td>
<td>10</td>
</tr>
<tr>
<td>Emphysema</td>
<td>0</td>
<td>18</td>
<td>0</td>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>Heart disease</td>
<td>36</td>
<td>6</td>
<td>4</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Hypertension</td>
<td>0</td>
<td>18</td>
<td>0</td>
<td>18</td>
<td>0</td>
</tr>
<tr>
<td>Migraine</td>
<td>0</td>
<td>18</td>
<td>0</td>
<td>18</td>
<td>0</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>3</td>
<td>14</td>
<td>3</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Stroke</td>
<td>34</td>
<td>7</td>
<td>3</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Ulcer</td>
<td>0</td>
<td>18</td>
<td>0</td>
<td>18</td>
<td>1</td>
</tr>
</tbody>
</table>

Group total 4,605 265 3,201 4,535
Population (in millions) 6.10 1.90 8.90 7.00
Mean groups per million 754.92 139.47 359.66 647.86

Note: Population figures for cities are from the U.S. Census Bureau Statistics [http://www.census.gov/foreign.pdf, retrieved September 20, 1996].

<sup>a</sup> Mean were computed by averaging group counts per million across city.  <sup>b</sup> Index represents prevalence-adjusted support measure derived from computing mean groups per million (across the four cities sampled) divided by prevalence, multiplied by 10,000.

make mutual support more the norm in Chicago than in Dallas.

To assess the relative consistency of supportiveness as a construct by diagnostic category, we computed Spearman rank correlations (r) for the four city counts. The resulting correlations were high. A reliability analysis indicated an alpha for the four cities of .89. Given this high degree of intercorrelation, we collapsed across cities to generate a population-adjusted mean and rank for each disease, included in Table 2. Not surprisingly, alcoholism ranked first, with AIDS second. The cancers followed, with breast cancer showing the highest levels of support and lung cancer the lowest. Finally, collapsed population-controlled counts were adjusted for prevalence (figures represented in Table 1) so that the resulting support indices also reflected the population sizes from which the participants were drawn.

The preponderance of support groups in the alcoholism category is at once predictable and noteworthy and so deserves specific mention. Of the 12,596 total groups identified for all of the conditions studied, across all cities sampled, AA groups constituted 10,966, or 87%, of the group counts. These numbers, and hence the AA story, are a testament to the potential strength and efficacy of mutual support: The largest number and degree of health behavior changes in the country are the product of a network of largely anonymous, expert-free, cost-free groups whose sole purpose is mutual support. It is also useful to note that the AA philosophy asserts that group participation is a lifetime commitment: Addiction is an incurable condition managed only by enduring vigilance. Although a detailed account of the AA literature is outside the focus of this article, multiple factors have been identified that describe self-help and treatment success in coping with addiction (e.g., Tucker, 1995).

What is striking is the degree, or range, in support seeking in general among illness categories after adjusting for prevalence. AIDS patients, for instance, are 250 times more likely to participate in a support group than hyper-tension patients. Breast cancer patients have formed over 40 times as many support groups as heart disease patients, whose conditions undeniably benefit from psychosocial and behavioral changes. Such contrasts raise questions about the motivations of participants.

Our methodology suffers from a few problems intrinsic to the self-help culture that make clear quantification inherently difficult. Comorbidity in both disease and sup-
port makes clean counts problematic. For instance, stroke is highly related to hypertension. It is evident, though, that those with high blood pressure will seek support after a stroke much more readily than before it. Individuals suffering from hypertension, moreover, have a higher probability of also suffering from diabetes or heart disease. It is unclear whether patients carrying more than one diagnosis tend to be involved in more than one support group. In some cases, support groups were not exclusively composed of individuals in the diagnostic category of interest. For example, in the case of support groups for anorexia, some (e.g., Overeaters Anonymous) included participants with bulimia and obesity problems as well.

A second unavoidable problem concerns the process of adjustment for the prevalence rates of the diseases. Given the relatively low participation rates of all patient types in mutual support, the observed ranks are heavily driven by the prevalence rates themselves. Despite the acknowledged problems, the methodology was the most valid means of assessing support group patterns without introducing significant bias. The observed participation patterns in these face-to-face groups prompted questions about how virtual avenues of support might elicit similar or different patterns among the same patient groups.

**Study 2: Frequency and Characteristics of On-Line Support**

As of 1996, approximately 15% of Americans (about 40 million) already had Internet access, with growth estimated at 20% per month (Ferguson, 1996). Moreover, interest in on-line participation is significantly driven by health issues. A recent Louis Harris poll conducted to assess the motives behind new subscriptions to on-line services found that health concerns were ranked first (reported by Ferguson, 1996). The social connections enabled by the advent of the Internet constitute a new forum of social support that has unknown, and largely unstudied, potential. For the patient, the availability of on-line support introduces a new dimension of social connection and access to information. For researchers, the observation of on-line support offers a unique window for understanding the kinds of experiences that patients wrestle with, from reluctant insurers to patronizing doctors, as well as histories of suffering, confusion, and misdiagnosis. A few examples from our Internet posts are featured below.

Dear Carol, Hi! I understand your concerns. I am 47 and I just survived my first heart attack. I too continue to think of one day or the next will be my last day. I weep for this because I have not danced at my daughter’s wedding and I planned to sit on a porch with my husband and I cling to this life with all of the intensity that I can muster. But I know your fear and I know your depression so very well. Whether or not I can make it past another twelve months without another episode is now the issue since I have survived the first month. Carol they just don’t know very much about women and heart disease—this much I know for sure. (AOL subscriber, heart disease bulletin board)

Was wondering if any women who have had breast cancer have noticed a correlation between stress in their life and the onset of the breast cancer? Two years ago my husband and I separated and the last year—the year from hell—I experienced a car accident, the realization that someone I loved was on the verge of schizophrenia, a creeping Tom invading my privacy, my father’s death, the loss of my job and financial security, and then breast cancer... After a while [sic] I wondered if it was worth living. I lost my zest and couldn’t find much joy in life.... Psychologically and emotionally, as most of you know who’ve been through similar things, I feel whipped out. I pray a lot and have good friends who help me as they can and also pray for me. (contributor to Internet support forum for breast cancer)

Let me give you my idea on how to be a good CFS [chronic fatigue syndrome] wife. Tell him to order pizza or something. Have him clean the exotic molds in the refrigerator. Prepare yourself. Stay in bed all day and make sure you are more interesting than the vixens he works with all day. ... Give him a grocery list and tell him to buy whatever he wants to drink. Feel free to cry about your day. Men love to comfort and protect. Go to sleep the moment he arrives. If he wants a clean house, he can visit a neighbor. (contributor to the chronic fatigue discussion list—Internet)

The reason they are calling your mother a Type II is because the first hour was 121 and the second 183. Two hours after eating is when your sugar levels should peak out. Because her levels were above 120 two hours after eating, she is probably a Type II. Since her bg [blood glucose] levels were down to 11 three hours later, it probably means that your mom has lazy organs like I do. She may be on meds, then again she may be able to control it with diet and exercise. Maybe you should go with your mom to the doctor and try to get all the information that you both need. The doctor probably won’t mind, and will probably be glad that her family has taken such an interest in her well being. (response to the daughter of a recently diagnosed diabetic on the Internet support forum)

Each individual account contributes to a larger collective narrative that paints a portrait of identity by diagnosis. With good reason, researchers in the fields of psychology, sociology, and anthropology are focusing on the narrative approach to understanding identity and culture in various groups. A comparison of virtual and actual support enriches a basic understanding of support-seeking patterns on the part of individuals coping with health problems.

The aim in this study was to identify those kinds of health problems that prompt higher levels of on-line participation and to determine what similarities would exist between virtual and actual avenues of support. Our strategy, as in Study 1, was not to assess the availability of all support resources for patients (e.g., friends, family, health care professionals, and coworkers) but to gain a broader perspective on those types of experiences of illness that cause patients to seek out others facing the same challenge. Using a method similar to that used for the city surveys, we measured support levels for the 20 studied conditions by counting all contributions to on-line forums by participants.
over a two-week period.\textsuperscript{3} Two on-line domains were chosen for monitoring: Internet newsgroups and their America Online (AOL) counterparts, bulletin boards. From these two venues, 37 virtual support groups were identified and monitored for a period of two consecutive weeks.\textsuperscript{3}

The Internet, at the time of the study, featured over 40,000 newsgroups, with dozens of new ones being generated daily. To determine which groups to monitor, we compiled a master list of all existing English language newsgroups (nationwide and/or international only, not regional) and then used keyword searches for each disease category. From the results of these searches, we could identify all groups that were deemed to be mutual support groups as opposed to groups that were forums for lobbyists, researchers, or other expert exchange. If more than one support group existed, we selected the group exhibiting the highest volume of exchange over a two-day pilot period.

The commercial nature of AOL's organization distinguishes it to a large degree from the groups found on the Internet. Groups present on AOL's "Health Channel" reflect the commercial or public service goals of large groups that would like to have a presence on that server (e.g., Arthritis Foundation, American Lung Association, various pharmaceutical companies). The pattern of emergence of newsgroups (or bulletin boards as they are known on AOL) is just the opposite of that of the larger Internet. Internet groups are organized by interested individuals, so no systematic commercial motives are part of that agenda. This makes for a source of unique patterning in the groups on AOL and the Internet, which is discussed more fully later.

The raw totals and adjusted indices of support, along with their ranks, are featured in Table 3. In those cases in which a condition lacked a forum, the number of posts was recorded as zero. Posts on AOL over the two-week period, for all groups studied, totaled 2,043, whereas posts on the larger Internet totaled 5,440. The highest rates of activity observed on AOL were for multiple sclerosis, followed by diabetes, and then by depression. The highest rates of activity on the Internet were for chronic fatigue syndrome, followed by diabetes, and then by breast cancer. The lowest rates of activity on both domains were observed for chronic pain, emphysema, and migraine. Chronic fatigue syndrome sufferers exhibited extremely high activity levels on the Internet, whereas no list was available for those sufferers on AOL. This contrast may reflect the imperfect meeting ground between consumer-driven organizational patterns on the Internet and the provider-driven evolution of AOL.

Rank correlations between the two forums approached but did not reach significance, $r_d(18) = .35, p = .13$. This finding makes sense in light of the fact that Internet and AOL support groups reflect different user bases. Using a method similar to that used for the city groups, we collapsed the two on-line measures within each diagnostic category and adjusted for prevalence in order to yield a more accurate reflection of the relative prevalence of online support behaviors. These figures are outlined in Table 3. Rank correlations of prevalence-adjusted on-line and face-to-face city indices were quite high, $r_d(18) = .70, p < .01$.

Several patterns emerged in the on-line forums that distinguished them from the metropolitan groups. First, alcoholism, which dominated the face-to-face samples, exhibited a much lower activity level on-line, ranking ninth and seventh on AOL and the Internet, respectively. This is understandable given the long tradition of actual support enjoyed by AA members, who may find virtual support a poor substitute for the group experience. Second, chronic fatigue syndrome, which did not emerge as a diagnostic category until 1988, had the highest activity level of all the Internet groups. In view of the high rate of use by multiple sclerosis sufferers as well, the on-line domain may be particularly useful in bringing together those who suffer from rare and debilitating conditions, in which getting together physically would present a number of practical barriers. Virtual support can be very attractive to those whose disability impairs mobility, and, more striking, the on-line community allows for anonymity. Potent social factors like physical attractiveness, vocal characteristics, ethnicity, and social skills are neutralized.

Despite these differences, raw counts for the two on-line measures were positively correlated with the collapsed measure of the city groups—$r_d(18) = .45, p < .05$ for AOL; $r_d(18) = .37, p = .11$ for the Internet (two-tailed in all cases)—suggesting that an underlying construct of support seeking does exist by diagnosis, with the different

\textsuperscript{3} From a methodological standpoint, it was unclear whether the appropriate comparison in this domain would be the number of unique contributors or the number of contributions in total. The resulting decision to count contributions was a judgment call based on the goal of having an index of active participation rather than participants. The virtual arena is also populated with a large number of "trollers," or individuals who read others' posts but do not contribute. It was felt that the overall amount of conversation was a more accurate reflection of social exchange than the number of members. In any case, post hoc analyses of the number of unique users per forum revealed that ranks of users per category and ranks of contribution totals per category exhibited a correlation of .95, suggesting that the different measures were comparable.

\textsuperscript{4} To determine which groups to monitor, we compiled a master list of all existing newsgroups (nationwide and/or international only, not regional) and performed keyword searches for each disease category. From the results of those searches, all groups that were deemed to be mutual support groups, as opposed to forums for lobbyists, doctors, researchers, or other expert exchange, were identified. In cases in which more than one support group was identified, the group that exhibited the highest volume of exchange over a two-day pilot period was selected. Most support groups for both physical and mental illness begin with the prefix "alt.support. For example, the arthritis support group is "alt.support.arthritis." The most notable exception to this trend was the most active support group for breast cancer, which is breast-cancer@msg.side.mhc.ca. The only difficult aspect in identifying the appropriate support forum emerged with respect to AIDS. In some senses, although new cases reflect a change in the demographics of AIDS, it has traditionally been strongly tied to the homosexual community. The newsgroup "alt.support.homonuclear" was monitored and found to have a substantial focus on the AIDS epidemic; however, to select the list as the forum for support would have misrepresented a significant portion of the discussion. The point to bear in mind is that AIDS, unlike any of the other diseases, encompasses lifestyle and sexual issues that make its discussion hard to contain, at least by diagnostic boundaries. Many groups were forums in which AIDS was discussed. "Acute.aids" was chosen because of its focus on AIDS and its lack of homosexual bias (which cannot really be considered any advantage, merely a necessity). A complete list of the selected newsgroups is available from the authors.
Table 3
Totals of On-Line Support Contributions for AOL and the Internet by Disease, Along With Their Ranks, as Well as Prevalence-Adjusted Indices of Overall On-Line Support Activity and Their Ranks

<table>
<thead>
<tr>
<th>Disease</th>
<th>AOL No. of contributions</th>
<th>Rank</th>
<th>Internet No. of contributions</th>
<th>Rank</th>
<th>Adjusted$^a$</th>
<th>Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>127</td>
<td>8</td>
<td>138</td>
<td>9</td>
<td>168.79</td>
<td>7</td>
</tr>
<tr>
<td>Alcoholism</td>
<td>37</td>
<td>9</td>
<td>270</td>
<td>7</td>
<td>12.39</td>
<td>11</td>
</tr>
<tr>
<td>Anorexia</td>
<td>61</td>
<td>10</td>
<td>251</td>
<td>8</td>
<td>294.34</td>
<td>4</td>
</tr>
<tr>
<td>Arthritis</td>
<td>156</td>
<td>6</td>
<td>77</td>
<td>12</td>
<td>3.57</td>
<td>15</td>
</tr>
<tr>
<td>Asthma</td>
<td>39</td>
<td>12</td>
<td>103</td>
<td>10</td>
<td>5.43</td>
<td>12</td>
</tr>
<tr>
<td>Cancer, breast</td>
<td>221</td>
<td>4</td>
<td>946</td>
<td>3</td>
<td>329.85</td>
<td>3</td>
</tr>
<tr>
<td>Cancer, colon</td>
<td>9</td>
<td>14</td>
<td>337</td>
<td>5</td>
<td>189.90</td>
<td>6</td>
</tr>
<tr>
<td>Cancer, lung</td>
<td>173</td>
<td>5</td>
<td>no list</td>
<td>18</td>
<td>219.54</td>
<td>5</td>
</tr>
<tr>
<td>Cancer, prostate</td>
<td>40</td>
<td>11</td>
<td>14</td>
<td>15</td>
<td>46.31</td>
<td>10</td>
</tr>
<tr>
<td>Chronic fatigue syndrome</td>
<td>no list</td>
<td>18</td>
<td>1,035</td>
<td>1</td>
<td>517.50</td>
<td>2</td>
</tr>
<tr>
<td>Chronic pain</td>
<td>no list</td>
<td>18</td>
<td>56</td>
<td>13</td>
<td>0.93</td>
<td>17</td>
</tr>
<tr>
<td>Depression</td>
<td>248</td>
<td>3</td>
<td>779</td>
<td>4</td>
<td>54.63</td>
<td>9</td>
</tr>
<tr>
<td>Diabetes</td>
<td>291</td>
<td>2</td>
<td>989</td>
<td>2</td>
<td>81.91</td>
<td>8</td>
</tr>
<tr>
<td>Emphysema</td>
<td>no list</td>
<td>18</td>
<td>no list</td>
<td>18</td>
<td>0.00</td>
<td>20</td>
</tr>
<tr>
<td>Heart disease</td>
<td>144</td>
<td>7</td>
<td>7</td>
<td>16</td>
<td>3.55</td>
<td>16</td>
</tr>
<tr>
<td>Hypertension</td>
<td>10</td>
<td>13</td>
<td>no list</td>
<td>18</td>
<td>.18</td>
<td>19</td>
</tr>
<tr>
<td>Migraine</td>
<td>no list</td>
<td>18</td>
<td>90</td>
<td>11</td>
<td>4.08</td>
<td>14</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>451</td>
<td>1</td>
<td>317</td>
<td>6</td>
<td>1,097.14</td>
<td>1</td>
</tr>
<tr>
<td>Stroke</td>
<td>0</td>
<td>18</td>
<td>31</td>
<td>14</td>
<td>5.17</td>
<td>13</td>
</tr>
<tr>
<td>Ulcer</td>
<td>2</td>
<td>15</td>
<td>no list</td>
<td>18</td>
<td>0.22</td>
<td>18</td>
</tr>
<tr>
<td>Total posts</td>
<td>2,043</td>
<td></td>
<td>5,440</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. Ranks assigned indicate a ranking of 1 for highest observed values. AOL = America Online.

$^a$ Online adjusted index was derived by computing mean total posts per condition [AOL + Internet/2], divided by prevalence, multiplied by 1,000.


Avenues of support constituting a kind of method variance. Both types of support are means by which social comparison is enabled: similar sufferers can tell their stories to sympathetic audiences and can exchange tips about the management of their conditions. Means of the two on-line measures computed for each condition exhibited a strong relation to the city patterns, $r(18) = .47, p < .05$. In a similar vein to the patterns observed in the metropolitan groups, breast cancer, depression, and diabetes were conditions in which talk (in the form of posts) occurred at relatively high rates, whereas talk by migraine, ulcer, and chronic pain sufferers was conspicuously absent from the bulletin boards.

Because city group participation and on-line participation rates were significantly correlated, we felt it would be useful to generate one comprehensive support index, across both on-line and actual groups, leaving out the prevalence adjustment that so strongly shaped rankings observed in Tables 2 and 3. Because of its extreme value, alcoholism was excluded. To convey a simpler picture, figures for all cancers were combined, and an overall cardiovascular disease category was generated by combining hypertension, coronary heart disease, and stroke. Both the population-adjusted city index (refer to Table 2) and the mean on-line indices (Table 3) were converted into $z$ scores. Means of those $z$ scores across the two support types were computed and are depicted in Figure 1.

As is evident in Figure 1, other than alcoholics, cancer patients exhibit the highest overall tendency to seek and offer support. Also notable were support levels for AIDS, diabetes, depression, and chronic fatigue. By contrast, extremely low levels of support were observed in the cases of ulcer, emphysema, chronic pain, and migraine. Support levels in the cardiovascular disorders, even as combined, are only slightly higher than those for anorexia, a condition whose prevalence is almost 1,000 times less prevalent. Some conditions, then, are noteworthy for the amount of talk they generate among sufferers, whereas others are not less noteworthy in their relative silence.

If migraines are as responsive to self-help as to medication, why don’t migraine sufferers get together? What kinds of suffering do not generate social comparison behaviors? Bearing in mind the shared and distinctive features of the two support venues and the markedly high consistency in tendencies to participate in support, our goal was to uncover the motives behind such patterns.
**Figure 1**
Summary Indices of Supportiveness Combining City and On-Line Measures

<table>
<thead>
<tr>
<th>Illness Type</th>
<th>All Cancers</th>
<th>Diabetes</th>
<th>AIDS</th>
<th>Depression</th>
<th>CFS</th>
<th>MS</th>
<th>All CVD</th>
<th>Anorexia</th>
<th>Asthma</th>
<th>Arthritis</th>
<th>Migraine</th>
<th>Chronic Pain</th>
<th>Emphysema</th>
<th>Ulcer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Z Score of City and On-Line Groups</td>
<td><img src="chart.png" alt="chart" /></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Indices represent means of Z scores associated with population-adjusted city groups and mean [America On-line and Internet] on-line totals. The ill-CVD category was derived by compiling coronary heart disease, hypertension, and stroke conditions. Alcoholism, although unquestionably the condition characterized by the highest support levels, was excluded because its extreme value would have suppressed all standard scores. CFS = chronic fatigue syndrome; MS = multiple sclerosis; CVD = cardiovascular disease.

**Study 3: Identifying Correlates of Support Seeking**

Social comparison theory asserts that affiliative behaviors increase in times of uncertainty or anxiety. The difficulty in predicting behaviors on the basis of such considerations is that the experience of anxiety issues from myriad causes—embarrassment, threat to life, pain, anticipated pain, financial burden, and so on. Our goal in this study was to identify sources of anxiety relevant to patients’ experiences of illness in order to understand which, if any, of these sources would be related to support seeking. Three broad areas of investigation served as the conceptual foundation of our inquiries: patient characteristics, (both psychological and demographic), health care burden (aspects of illness that increase medical care usage), and social burden (the interpersonal dimensions of the illness experience). The goal was to clarify whether support seeking was primarily motivated by personal, social, or health-care-induced anxiety.

A number of personal factors are involved in care-seeking behaviors. For instance, some segments of the population exhibit higher levels of concern about their health status. The elderly and women, for example, use health care services more extensively than do young adults and men (Aday & Andersen, 1974). AA participants with supportive social networks exhibit higher adherence levels to the self-help program (Tucker, 1995). Individual differences, such as sociability or commitment to work, are also related to support seeking. Prior studies of self-help participants found that they have higher levels of social skills than those of nonparticipating counterparts (Taylor, Falke, Shoptaw, & Lichtman, 1986). One question, then, was the degree to which some patient groups would be perceived as generally friendlier than others.

A second consideration centered on illness factors that determine patients’ perceived self-care needs and treatment- adherence patterns. The most widely cited model of patients’ schemas about illness suggests that such structures fall into five dimensions: illness identity, time course, consequences, causal models, and likelihood of cure (Leventhal, Meyer, & Nerenberg, 1980). Some items characterized under headings of health care salience and patient burden were generated to capture the anxiety-relevant aspects of illness and treatment consistent with Leventhal et al.’s model of illness schemata. Examples include degree of life threat, ideas about cause, burden on patient to manage, and social stigma.

Finally, some items were included to assess the interpersonal impact of a given illness category. Examples include embarrassment, stigmatization, and disfigurement. We hypothesized that social anxiety might be assuaged through support group participation.

Judges’ ratings were obtained from four health care experts indicating, on a scale of 1 to 7, to what degree each description accurately depicted each of the 20 diseases or the patients that suffered from them. All judges had at least a master’s degree level of training in nursing, public health, or medicine. One rater was an MD; the three other raters (one PhD in nursing, one MS in nursing, and one MS in public health) were nurses on faculty at a large teaching hospital. Overall, agreement among the judges was adequately high, yielding a mean alpha of .72 across the 16 items. We averaged each rating across judges and computed subsequent correlations with support levels to identify which factors, if any, were associated with support seeking.

As shown in Table 4, having an illness that is embarrassing, socially stigmatizing, or disfiguring leads people to seek the support of others with similar conditions. The most striking associations, then, between support seeking and illness features centered around the *interpersonal* consequences of illness: Conditions described as embarrassing, socially stigmatizing, and disfiguring were associated with higher levels of support of both kinds. In fact, embarrassment around discussion of the illness emerged as the strongest association with support of both kinds. This pattern of results, on the surface, conflicts markedly with prior work in social comparison theory. Embarrassment has been widely presumed to weigh against affiliative behavior (Saroff & Zimbardo, 1961; Teichman, 1973), yet alienation from one’s usual support network may be precisely the kind of social anxiety that in turn increases the value of the mutual support context.

Aspects of illness associated with cost of treatment and loss of life were positively associated with support seeking in the city groups but not in the on-line forums.
The threat of death and the experience of costly medical treatment are the two factors most highly correlated with participation in face-to-face support groups. The personal features grouped as patient characteristics showed no significant relations to support behaviors of any kind. None of the personal characteristics we considered—friendliness of patients, illnesses directly related to aging, or illnesses that strike women—were associated with supportive seeking. This result stands in contrast to earlier findings by Taylor et al. (1986) reporting higher participation rates by women. Online support was unique in its correlation with importance of patient’s attitude to outcome. This pattern of findings suggests that virtual support occurs at higher rates among patients whose conditions, although not necessarily life threatening, are debilitating in ways less responsive to purely medical care.

**Discussion**

The aim of these studies was to identify patterns of patient support, both in face-to-face encounters and through the use of on-line options. The tendency to participate in support groups was highly consistent by category across cities. The highest levels of support were found in the cases of alcoholism, AIDS, breast cancer, and anorexia, and the lowest levels of support were found in the cases of hypertension, migraine, ulcer, and chronic pain. Wide disparities were observed in (a) the overall tendency to participate in support groups between cities and (b) the tendencies of patients with certain conditions to seek or not to seek support, particularly after adjusting for prevalence.

Comparable patterns emerged in the on-line domain. In that case, a modest relationship was found between the two venues of virtual social exchange. The highest levels of support activity were exhibited by sufferers of multiple sclerosis, chronic fatigue syndrome, breast cancer, and anorexia. The lowest activity levels were observed for sufferers of chronic pain, ulcer, hypertension, and emphysema. On-line and face-to-face support patterns were significantly correlated, suggesting that broad tendencies to seek support do vary by diagnostic category. Standardized measures of face-to-face and on-line support, when collapsed, revealed a broad picture of variations in support seeking by diagnosis. Alcoholism, cancer, AIDS, depression, and diabetes are conditions that have given rise to the formation and maintenance of mutual support forums.

These tendencies, according to correlations with judges’ ratings, may be spurred by the interpersonal consequences of illness, specifically, embarrassment, stigma, and disfigurement. Actual groups were unique in their association with conditions rated as terminal and costly to treat. This kind of seriousness index was not evident in motivating on-line support. On-line forums appear to be slightly more oriented around conditions poorly understood and somewhat overlooked by the medical community. Those confronted with grave concerns may feel more acutely the need to experience the physical presence, the validation, and the sense of belonging that come with actual encounters. Virtual support may have its limits.

According to social comparison theory, in conditions of uncertainty or anxiety, affiliative motivation should be increased, except under conditions of embarrassment. In particular, individuals would prefer the company of others who are in a similar situation when experts are absent. These postulations are fitting in the case of the on-line forums, in which a relative amount of anonymity is present, and thus confiding can occur without immediate social repercussions. In the case of the city support groups, however, hypotheses about lowered support seeking in conditions associated with embarrassment were poignantly disconfirmed. These groups are populated by individuals whose illnesses, either by their very nature or as a result of treatment (e.g., mastectomy), have forced them to experience embarrassment and social stigmatization. The seriousness of their conditions, the weight of their illness impact, and the degree of readjustment required under the circumstances suggest motives only partially captured by terms like ambiguity and anxiety. In these cases, the patients’ experiences set them apart from their immediate social setting and propel them toward others who have been similarly marked.

The findings surrounding support-group participation suggest that laboratory investigations of social motives lack some ecological validity: It is not a great challenge for a student to anticipate the experience of embarrassment and decline the opportunity to share this with another in a highly controlled lab study. The experience of embarrass-
ment in everyday life, however, carries with it the ongoing burden of a barrier that results in chronic emotional arousal accompanied by the suppressed desire to talk with others. Such social barriers represent a significant health risk (Cole, Kemeny, Taylor, & Visscher, 1996; Pennebaker, 1997).

On the basis of the observed patterns, anxiety is a necessary but not sufficient condition for support seeking. Heart attack survivors, for example, report high levels of anxiety in the aftermath of their attacks, feeling as though their lives could have suddenly ended and may end in the near future (Cay, Vetter, Phillip, & Dugard, 1972), yet cardiac patients are not seeking to share feelings with others (ranking 15th in adjusted support). The marked lack of support in heart disease patients is consistent with prior observations of personality profiles associated with that condition: The Type A construct portrays a hostile, interpersonally suspicious, hurried, or depressed temperament ill-suited to the kinds of disclosure that are standard in support groups (for a review, see Smith, 1992).

Conversely, the profile of the cancer-prone personality is one ideally suited to a support forum because of its characterization as friendly, cooperative, and tending to suppress expression of negative emotion (Greer & Watson, 1985; Temoshok, 1987). It is noteworthy that, although more women will die from heart disease every year, and although more women are currently living with a history of heart disease, our findings indicate that breast cancer patients participated in support groups at rates 40 times higher than all heart disease patients, male or female.

**Directions for Future Research**

It is interesting that the striking differences in support seeking between heart disease and cancer patients harken to some of the traditional personality–situation debate. As the Type A and cancer-prone constructs suggest, certain features of a “disease personality” may dictate how individuals avoid or seek out others. Conversely, the very nature of the disease may differentially threaten friends of the person with the disease. For example, one’s friendship network may be more frightened or helpless in hearing about cancer or AIDS than in learning that one of their own has high blood pressure or has suffered a heart attack (cf. Bolger, Foster, Vinokur, & Ng, 1996; Petrie, Weinman, Sharpe, & Buckley, 1996).

One way to gain insights about the validity of controversial profiles such as Type A and the cancer-prone personality would be through closer analysis of linguistic styles revealed in on-line forums. Disclosure styles have been linked to markers of immune function and cardiovascular reactivity (Christensen & Smith, 1990; Kamen-Siegel, Rodin, Seligman, & Dwyer 1991). For example, a recent study of on-line disclosure styles found that consistent with prior observations of cancer patients (e.g., Watson, Pettingale, & Greer, 1984), virtually no negative emotion was expressed in such forums (Davisson & Pennebaker, 1997). Studies of disclosure styles associated with different patient populations will make a significant contribution toward the psychosomatic literature focused on the relationship between personality and illness.

Another obvious extension of the research would focus on elucidating distinctions in disclosure styles between those on-line groups that include an authority figure and those that do not. Our results suggest that conditions lacking some medical legitimacy are associated with higher participation levels. As the virtual community evolves, it may soon be possible to distinguish between the kinds of discourse that occur among patients that also have a doctor present and the kinds of exchanges occurring when such an authority figure is lacking. Social comparison would indicate that group cohesion is higher when the authority is absent. Changes in disclosure styles when authority figures are present may shed valuable light on what patients feel able to discuss with doctors and what they can’t.

Another direction for future research concerns the relationship between Internet support participation and other indices of health and health-related behaviors. Recent studies have reported that higher rates of Internet use were associated with poorer measures of social adjustment, including loneliness and smaller social circles (Kraut et al., 1998). A constant concern in social-support research has been the distinction between support network size and support network quality (Stroebe & Stroebe, 1996). Internet forums represent a new hybrid for participants in which size is large but quality is largely unknown. People suffering from illness benefit from social support. If Internet use is a substitute for actual emotional support, then patients may be engaging in shallow forms of exchange when more substantial ties could be built face-to-face, to the peril of both psychosocial and physical well-being. Comparisons between virtual and actual social behaviors will provide insights about how the Internet contributes to the configuration of individuals’ social worlds.

**Implications for Policy and Practice**

As with other correlational designs, the results obtained in this broadly based analysis of patient support groups are suggestive, not conclusive. Although strong correlations were found between indices of social marginalization (embarrassment, disfigurement, stigma, and life threat) and support-group participation levels, the reality of participation motives is most likely a more complex interaction of illness, individual differences, and cultural norms. Foundations, hospitals, patients, and doctors can significantly alter the viability of support groups. The investigations convey only a part of the picture. They do, however, indicate the value of attempts to observe, in an ecologically valid way, the social patterns of individuals who may not be aware that they or their activities are part of a larger movement. The value of the approach lies in observing social behaviors, even collective ones, from an epidemiological perspective.

An aspect of the support group picture that needs additional attention is analysis of the character and purpose of the groups. Prior reports on other kinds of support groups indicate that group purposes frequently evolve over time into watchdog organizations, lobbying arms, or fund-
raising outlets (Chesler & Chesney, 1995). When a support group converts from one of emotional and informational support into one of social activism, what does it do for members? The lifetime of membership participation and group life in general is highly variable. As noted earlier, AA membership is a lifelong one. Other groups are more temporary in orientation. As with illnesses, people have schema about the duration of support needs. For psychologists, the dynamics of these groups over time offer insights about social theory and about patient needs.

The self-help movement, both in face-to-face and virtual arenas, has tremendous therapeutic potential. Apparently, relative increases in social marginalization result in a desire to compare notes with similar others, despite the experience of embarrassment. As such, it may be possible to draw on the cohesive power that stigma apparently generates. Recruitment efforts for rehabilitation programs or health behavior change may be more successful if reference to one or more of the stigmatizing aspects of a condition is made. Adherence over time may be increased if medical programs integrate more opportunity for exchange around the human side of health and illness. Outside health care, other marginalized groups, such as immigrants, may be more effectively integrated with a modest push toward group involvement.

Although self-help and professional help are often perceived as mutually exclusive, the data indicate that such perceptions are misleading: Over 60% of groups describing themselves as self-help are professionally facilitated. This apparent contradiction should be more fully explored. Group participants may not be resistant to professional input; rather, they may need to speak and be heard about issues not addressed within the health care setting. Several important questions emerge from the lay and professional perspectives on mutual support. What factors are important to patients helping patients, as opposed to professionals helping patients? What features of professional input contribute to optimal outcomes? What combinations are optimal for various patient groups? What are the cost benefits associated with group approaches to health care? Physician enlistment could double or triple support group participation rates, and psychological expertise could heighten effectiveness in emotional support, health behavior change, and patient prognosis. The clinical potential of group support in combination with professional guidance is largely unknown.

Within contemporary health care, support group participation patterns are particularly relevant at this juncture in history given the disparity between the costs of health care and the unmet needs of many patients. The culture of institutional health care is still far from embracing psychological support into health care delivery, despite overwhelming empirical justification (for an excellent commentary on these issues, see Morgeson, Seligman, Sternberg, Taylor, & Manning, 1999). On the other hand, the culture of psychology has been focused around treatment of mental, not physical, ailments. Support groups represent one of the most adaptive permutations of the health care dilemma, allowing sufferers to gather the information most valuable to them—stories of similar experience and endurance. These investigations indicate that support groups are particularly valued by individuals whose lives and social identities have been put at risk. A fuller appreciation of the social context of illness enriches our theoretical understandings of social support and social comparison, while offering practical insights about a more appropriate match between health care delivery and the health care sought by patients and their families.

Both the methods and results of these studies have relevance for a number of concerns common to all psychologists: social comparison, group formation, health care, effects of stigma, and disclosure processes. The most interesting aspect of the study is also the most problematic: A constant concern for researchers is that balancing act of conducting research that draws on prior theoretical and empirical foundations while asking questions interesting enough to have real-world relevance. Support groups constitute a category with fuzzy boundaries, and as such they make scientists uneasy. In the interest of elegance and experimental control, we often prefer mutually exclusive categories and singular causal models. The goal is usually to isolate the hypothesized active agent in a particular phenomenon. At broader levels of analysis, though, such approaches lack validity, ignoring the realities of a society in which richly overlapping categories are everywhere. In this case, the most rigorous methodology was also a less controlled one. Support groups cannot be replicated in the lab, but the tendency of some types of patients to seek each other’s company more than other types of patients, despite the noise in the imperfect categorizations, emerges statistically as a clear pattern replicated across cities. We believe that psychologists should be encouraged to err more often on the side of real-world complexity in order to serve more effectively the society they attempt to observe.

REFERENCES


