

Influence of Health Beliefs and Stigma on Choosing Internet Support Groups Over Formal Mental Health Services

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Objective: As the Internet has become a ubiquitous tool for health information, the use of Internet support groups for mental health concerns has grown. Despite the widespread use of these groups, little research has examined the efficacy and effectiveness of online communities for ameliorating mental health symptoms or factors that prompt people to seek online support rather than formal treatment. Our study addresses this gap in the literature by investigating Internet support group use as an alternative to formal mental health services. **Methods:** Logistic regression was conducted with data from the 2008 National Survey on Drug Use and Health (NSDUH) to examine relationships among treatment beliefs, practical variables such as time and affordability, stigma, and use of Internet support groups among 2,532 survey participants who reported a need for mental health treatment but were not receiving formal services. **Results:** Four significant predictors of Internet support group use emerged: fear of being hospitalized or taking medication (adjusted odds ratio [AOR]=8.81, 95% confidence interval [CI]=4.25–18.27), inadequate insurance coverage (AOR=3.22, CI=1.44–7.20), age 26–34 years (AOR=.22, CI=.07–.69), and age 35 or older (AOR=.21, CI=.08–.56). **Conclusions:** Fear of coercion and the costs of traditional mental health services were important predictors of Internet support group use. The finding that inadequate insurance coverage prompted people to seek Internet support aligns with a substantial literature regarding lack of financial resources and reduced access to treatment. Individuals' fears of hospitalization and of taking medication suggested that they may view formal treatment as potentially coercive. Further work is needed to decrease public stigma regarding mental health services and the conditions under which involuntary treatment occurs. (*Psychiatric Services* 63:370–376, 2012; doi: 10.1176/appi.ps.201100196)

The Internet is an omnipresent source for health information. Web sites such as WebMD.com that provide interactive, searchable general medical and mental health information have proliferated (1), and millions of Internet searches

regarding general medical health, mental health, and treatment are conducted daily.

An estimated 22%–46% of individuals will experience diagnosable mental disorders during their lifetimes (2–4). Approximately one-third (36%) of

individuals with such diagnoses will receive formal treatment (5,6). Conversely, a majority of individuals with mental disorders will not receive formal services. Various factors may contribute to low rates of treatment, including the increasing prevalence of alternatives such as online Internet support groups. Increasingly, individuals are seeking nontraditional, online mental health services. These alternative services offer several advantages, including greater convenience, reduced transportation time, lower costs, anonymity, and reduced exposure to stigma (7–10).

The majority of research regarding online treatment for mental health concerns has focused on therapist-guided online individual interventions. Therapist-guided Internet interventions have demonstrated effectiveness in treating several mental disorders, including panic disorder (11), posttraumatic stress disorder (PTSD) (12), pathological gambling (7–13), addictions (7), and depression (14,15). Meta-analyses of therapist-guided online therapies demonstrate results similar to those of face-to-face psychotherapies, although effect sizes for online therapies vary across disorders—for example, effect sizes of .80 have been found for PTSD and panic disorders and of .17 for behavioral issues such as weight loss (16). The effectiveness of online interventions also varies by population, with youths and elderly individuals benefiting least of all age groups (16).

Internet support groups differ from therapist-guided online interventions. These online communities con-

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sist of networks of individuals who post questions and host discussions related to topics such as depression, anxiety, eating disorders, suicide, and self-harm. Online discussions typically are moderated by people without professional mental health training. Regulation of Internet support groups varies, with some requiring registration and others open to any participants.

The efficacy of non-therapist-mediated Internet support groups has been underinvestigated. Nonexperimental studies indicate that Internet support groups are not associated with improvement in depression symptoms, even though users perceive themselves to be emotionally supported by their participation (17). However, one experimental study of online, self-help, cognitive-behavioral therapy has demonstrated that an online modality performed better than an information-only control condition (18).

Limited research has been conducted to examine factors that prompt individuals with mental health concerns to seek online support (19). The health belief model offers a useful framework for understanding what draws people to use Internet support groups. According to the health belief model, two key health beliefs influence personal decisions to pursue treatment: threat perception and behavioral evaluation (20–22). Threat perception comprises an individual's perceived susceptibility to a health problem and the anticipated severity of the resulting consequences (20). Behavioral evaluation subsumes the relative valuation of the benefits of a recommended health behavior minus the costs and barriers associated with that behavior.

Expansions of the original health belief model have used personal and contextual information to augment health belief variables in predicting service use. According to Andersen's behavioral model of health service use (23), predisposing characteristics (such as personal and social demographic characteristics), enabling resources (such as time and money), and perceived need are additional determinants of service utilization. Tak-

en together, health belief and service use models offer a powerful explanatory framework that helps predict use of health services; however, they have not been used to examine decision making related to the use of Internet support groups for mental health concerns. This study examined the following predictors of Internet support group use among respondents to a national survey: health beliefs regarding formal treatment, practical barriers (such as time, transportation, and affordability), and stigma.

Methods

We analyzed data from a subsample of respondents to the 2008 National Survey on Drug Use and Health (NSDUH) 2008 (24). The deidentified data were exempt from institutional review board review and have been archived at www.icpsr.umich.edu. The NSDUH measures the prevalence and correlates of drug use in the United States with a nationally representative sample of 55,739 persons ages 12 and older. Although the primary purpose of the NSDUH is to assess alcohol and drug use, a subsection of this survey focuses on mental health disorders, impairment related to mental health symptoms, and use of formal and alternative mental health treatments. Data used in this study were drawn from a subsample of 2,532 respon-

dents ages 18 and older who responded affirmatively to the following question: "During the past 12 months, was there any time when you needed mental health treatment or counseling for yourself but didn't get it?" Participants were provided with a list of reasons for not obtaining formal treatment and were asked to give a yes or no response to indicate whether each reason factored into their decision about treatment. [A copy of these questions is available online as a data supplement to this article.]

Respondents were asked whether they used any alternative services for mental health concerns during the previous year. [A sampling diagram is available as an online supplement to this article at ps.psychiatryonline.org.] The dependent variable in this study was the use of Internet support groups as an alternative to formal mental health treatment. Variables from the aforementioned series of yes-no questions that assessed health beliefs (such as beliefs about treatment effectiveness and handling symptoms without treatment), practical issues (such as time and affordability), and stigma (such as not wanting others to find out and concern about negative effect on employment) were evaluated to determine whether they related significantly to use of Internet support. Univariate

Table 1

Reasons given by respondents to the 2008 National Survey on Drug Use and Health for not receiving formal mental health treatment^a

Reason	N	%
Practical obstacle		
Could not afford	1,106	44
No insurance coverage	172	7
Inadequate insurance coverage	222	9
Not knowing where to go	471	19
No transportation or too far to travel	110	4
Lack of time	365	14
Health beliefs		
Treatment not needed	218	9
Treatment would not help	252	10
Concerns about confidentiality	231	9
Could handle problem without treatment	698	28
Fear of hospitalization/medication	324	13
Stigma		
Negative effect on job	169	7
Not wanting others to find out	188	7
Neighbors' or community's opinion	276	11

^a N=2,532. Frequencies are greater than 2,532 because respondents could endorse multiple reasons for not receiving formal mental health treatment.

Table 2

Demographic characteristics of respondents to the 2008 National Survey on Drug Use and Health

Characteristic	No formal mental health services (N=2,532)		Internet support group users (N=86)		Internet support group nonusers (N=590)	
	N	%	N	%	N	%
Race-ethnicity						
White	1,813	72	66	77	425	72
African American	271	11	11	13	63	11
Hispanic	262	10	1	1	62	11
Other	186	7	8	9	40	7
Sex						
Male	725	29	17	20	144	24
Female	1,807	71	69	80	446	76
Age group						
18–20	581	23	26	30	93	16
21–25	922	36	33	38	201	34
26–34	420	17	10	12	110	19
≥35	609	24	17	20	186	32

frequencies summarizing reasons why respondents did not use formal services are presented in Table 1.

Logistic regression was conducted with R version 2.12.2 (25) to examine the relationships among health beliefs, practical variables, stigma, and Internet support group use. Person-level weights provided by the Substance Abuse and Mental Health Services Administration and the U.S. Department of Health and Human Services were recalculated to reflect the final subsample of respondents used in this survey. The recalculated sample weights were designed to preserve the proportional representation of each participant in the subsample without artificially inflating statistical power. First, the sum of the weights for all respondents was used to estimate the size of the total target population: $\sum_i w_i$ = estimated size of the target population, where the summation included all respondents in the 2008 NSDUH. Subsequently, new weights were calculated to reflect the sample size of 676 individuals who responded to the Internet support group use question:

$$\frac{w_{i(\text{new weight})} = 676 \times w_{i(\text{new weight})}}{\sum_i w_i \sum_i w_{i(\text{new weight})}} = 676.$$

Results

A total of 2,532 respondents reported having a perceived need for mental health treatment but not seeking it

during the previous 12 months. Among this group, 676 individuals responded to the question regarding use of an Internet support group as an alternate form of mental health treatment during the same period. Of these, 86 people responded affirmatively that they had used Internet support instead of formal treatment. A majority of respondents across all subgroups (those who did not seek formal treatment, Internet support group users, and Internet support group nonusers) were white, female, and 18–25 years old (Table 2).

Four predictors (Figure 1) were significant in the regression model: fear of being hospitalized or of taking medication (adjusted odds ratio [AOR]=8.81), inadequate insurance coverage (AOR=3.22), age category 26–34 years (AOR=.22), and age category ≥35 years (AOR=.21). Confidence intervals are reported in Figure 1.

Fear of being hospitalized or of taking medication was associated with more than eight times greater odds of Internet support group use, whereas inadequacy of insurance coverage was associated with just over three times greater odds of Internet support group use. Adults age 26 and older were less likely than adults ages 18–20 to turn to support groups on the Internet. Stigma variables did not predict Internet support group use.

Discussion

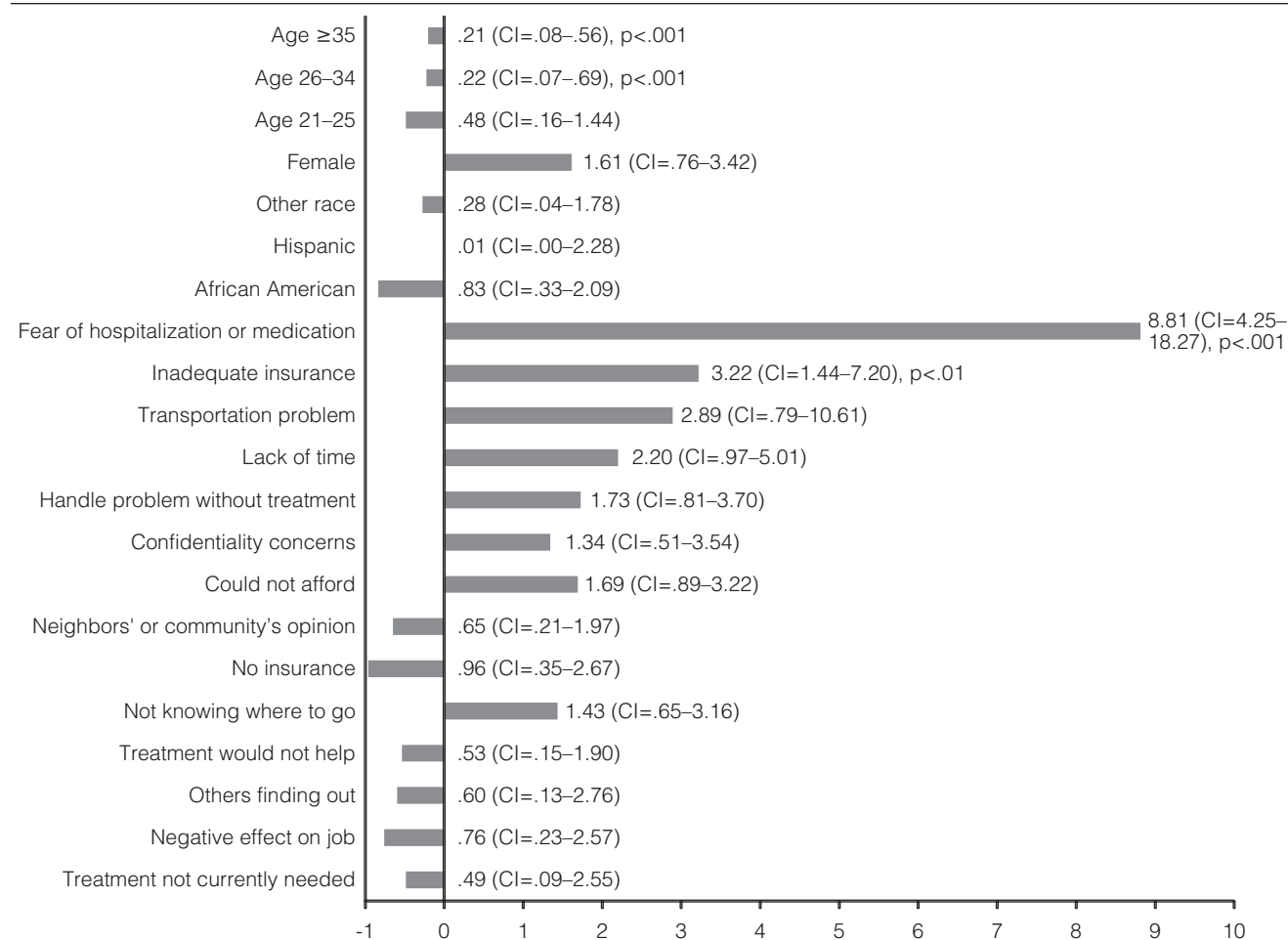
Our findings indicate that inadequate insurance coverage, fear of hospitalization or of taking medication, and younger age were significant predictors of Internet support group utilization in lieu of formal mental health services. These findings raise important concerns, given that the efficacy and effectiveness of Internet support groups for psychological problems has not been established.

The significant association between inadequate insurance coverage and use of Internet support groups among individuals who report not receiving formal treatment is consistent with existing literature regarding health insurance and access to medical and mental health treatments. It supports the “enabling resources” component of the behavioral model of health service use (23), which posits that treatment disadvantages (financial burden, for example) affect decisions to use services. Research has shown that individuals who are uninsured or underinsured receive either no treatment or sporadic treatment for mental health problems (26–28). Furthermore, higher copayments required under various insurance plan benefit structures are negatively associated with medication adherence (29) and mental health follow-up care (30). Concerns about insurance and finances are among the most commonly reported barriers to accessing mental health services (31). Thus it is not surprising that people may turn to the Internet as a cost-saving means of receiving support for psychological difficulties.

Fear of being hospitalized or being required to take medications was the strongest predictor of turning to Internet support group use instead of formal services in our study. This finding supports the behavioral evaluation component posited by the health belief model, in which perceived consequences of an illness are weighed against the costs and benefits of treatment (20–22). Among those who have not received formal treatment, it is possible that the fear of losing personal autonomy associated with treatment is juxtaposed unfavorably against potential bene-

Figure 1

Log odds of Internet support group use in a subsample of respondents to the 2008 National Survey on Drug Use and Health



fits of treatment. This is noteworthy, given that the study sample came from a subset of individuals who reported having concerns regarding their mental health yet did not receive treatment for those concerns. It raises the possibility that individuals who choose not to receive treatment may view mental health services as potentially coercive or restrictive, a concern that is avoided in the anonymous context of the Internet.

A well-replicated finding in mental health research is that people who have been treated for serious mental illness are likely to experience various degrees of coercion (32,33) and exhibit concern about future coercive treatment (34–36). This concern is associated with a reduced likelihood of seeking medical services, even for life-threatening general medical illnesses (37), and is the

source of debate in legal, psychiatric, and psychological arenas (38). Although the majority of research regarding fears of the consequences of mental health treatment has been conducted with mental health consumers, several studies have demonstrated that these fears are also a concern among the general public (39–41) and interfere with treatment seeking (31).

Our finding that older age groups (≥ 26 years old) were less likely than 18- to 20-year-olds to use Internet support is consistent with existing research regarding how the Internet is used by youths and young adults experiencing psychological distress (42,43) and aligns with general knowledge about the Internet's role in the social lives of younger individuals. The behavioral model of health service use (23) suggests that predis-

posing characteristics (such as age) have substantial bearing on treatment decisions. In this study, age was relevant to the decision to use the Internet instead of formal treatment and may reflect the ubiquitous nature of the Internet as a social medium in the lives of young people. Particularly concerning in this regard are studies suggesting that younger people receive fewer benefits from Internet-based mental health interventions than older users do (16). Adolescents and young adults are a subgroup that is especially vulnerable to catastrophic outcomes such as suicide (44), yet they are more likely than older people to be attracted to Internet support.

Stigma was not a significant predictor of Internet support group use in this study. This is inconsistent with previous research suggesting that

those who have experienced past stigma or who fear future stigmatization may opt for anonymous support (45,46). Further research is needed to understand why stigma was not associated with Internet support group use in this NSDUH subsample. One explanation is that previous research has been conducted with selected samples of individuals with problems that were difficult to hide—for example, the suicide of a loved one (45). In contrast, participants in the NSDUH came from a general population sample that was not selected for specific disorders or social problems. Regardless, social isolation has important clinical and societal consequences in that stigma may restrict intervention options for people who have serious mental health problems.

Our study highlights relationships between predisposing characteristics (age, for example), enabling resources (such as inadequate insurance coverage) and concerns about treatment (such as fear of hospitalization or taking medications) that predict use of Internet support in lieu of formal mental health treatment. Further research efforts to elucidate the efficacy and effectiveness of Internet support groups for specific populations are important given persistent questions about possible iatrogenic effects of online supports. For example, Internet support group abuses have been noted in documented cases of falsified suicide and death by purported Internet support group members who infiltrate discussion groups and misrepresent themselves (47). These incidents, as well as the potential for negative interactions between message posters (48) and sites that promote or normalize self-injurious behavior (42,49), carry significant clinical implications for individuals experiencing psychiatric symptoms.

Furthermore, the asynchronous nature of Internet support group communication presents a potential concern during mental health crises. Synchronous communication may be more paramount for users who seek support during times of crisis. Currently, little research evidence is available regarding the efficacy or ef-

fectiveness of Internet support groups for users experiencing mental health crises (50).

However, advantages of Internet support group use have been documented. Online groups can provide individuals with emotional support and information (51), empowerment (52), and anonymity (53). Internet support groups reduce transportation costs and may increase accessibility of support (54). The Internet offers the potential for communicating in a social arena that differs from usual interpersonal contexts, offering potential protection from stigma (52). Furthermore, Internet groups may offer opportunities for support to people whose expectations of stigma erect barriers to engagement with formal services (46). Internet groups may also be a valuable resource for members of marginalized subgroups (42).

This study had limitations common to secondary data analysis. Individuals provided yes-no answers to questions regarding their reasons for not seeking formal mental health services. More finely grained responses may be informative for evaluating the degree to which people are influenced by stigma, financial constraints, and practical obstacles to treatment. In addition, the NSDUH was designed to assess substance use, psychiatric symptoms, and service utilization; it was not designed specifically to examine health beliefs and their relationship to the use of Internet support groups. Detailed surveys that focus on these relationships are needed to outline more definitively the advantages and disadvantages of formal treatments versus online supports.

Item content was combined across several items for ease of survey administration. For example, the combined item “fear of hospitalization/taking medicine” may represent two unique constructs to which survey participants would respond differently if the presentation had been separate. Further research is needed to examine whether individuals view these aspects of mental health treatment differently in deciding whether to seek services.

Further research is needed to re-

fine our measurement of the role of finances in decisions regarding formal treatment. Specifically, lack of affordability, absence of mental health insurance coverage, and inadequacy of insurance coverage may play different roles in decisions to use formal treatment versus Internet support. We were unable to examine these issues within the parameters of this survey.

Finally, the sample included only 86 individuals who endorsed using Internet support groups instead of formal treatment services. Although the sample size provided sufficient power for the analyses presented herein, it may not have captured fully the characteristics of people who use the Internet for psychological support (42). Future studies are warranted to evaluate characteristics of this population of Internet support group users as well as to establish whether Internet support groups are efficacious and effective.

Conclusions

This study sought to increase understanding of a nascent and underinvestigated alternative mental health service. Use of the Internet for mental health information and support has proliferated yet has received little empirical attention. Findings from this study indicate that inadequacy of insurance coverage, fear of hospitalization or of having to take medication, and younger age were associated with the choice to use Internet support groups rather than formal mental health services among respondents who had not sought treatment. Internet support groups are not well understood in terms of their ability to provide relief from psychiatric symptoms. Both supportive and iatrogenic aspects of Internet groups have been reported in the literature; it remains unknown which Internet support groups are helpful for whom and for what types of mental health problems. In addition, education and advocacy are needed to outline the boundaries surrounding hospitalization and the prescription of psychotropic medications so that potential consumers are not discouraged from seeking formal services due to fears of coercion and loss of autonomy.

Acknowledgments and disclosures

The authors report no competing interests.

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