

**ONLINE SUPPORT FOR  
CAREGIVERS OF PEOPLE WITH  
A MENTAL ILLNESS**

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*This article reports on an online self-help group for caregivers of people with a mental illness. A discourse analysis was conducted using 417 messages contained within an 18-month period. Messages that had a primary focus of disclosure (N = 160) and providing information or advice (N = 89) were the most frequent. The content of messages was also examined. Discussion of emotions and diagnoses were found in 42% and 34.6% of the messages, respectively. A review of the current status of online self-help groups and implications for practice are also provided.*

An overhaul of the American mental health system now allows the majority of adults with a mental illness to live in the community rather than state hospitals. A broad range of placements exists, ranging from independent apartment living to supported housing projects. Living with family is also found under the purview of community placements. It is estimated that 50–70% of adults with a mental illness return from hospitals to live with their families (Johnson, 1990; Potasznik & Nelson, 1984). This range does not include those who are currently living with their families but have not received hospitalization. Skinner, Steinwachs, and Kasper (as cited in Lefley, 1996) surveyed member families of the National Alliance for the Mentally Ill (NAMI). Based on this study, they reported that 41.7% of adults with a mental illness live with their families. Many families still provide much care for the individual with a mental illness, regardless if he or she resides at home.

In a study by Lamb (as cited in Johnson, 1990), it was reported that two thirds of adults with a mental illness in the United States receive care from their family members.

Since deinstitutionalization occurred, there have been a number of advances in psychiatric services, benefiting both people with a mental illness and their families. The introduction of more effective neuroleptics, an antecedent to the policy change, have improved positive and negative symptoms in schizophrenia, reduced the frequency of psychiatric decompensation and curtailed the length of hospitalizations. Intensive case management services that recognize families as an asset have replaced many of the well-intentioned theories that blamed families for causing mental illnesses. Public education programs are in place to reduce the stigma attached to people with a mental illness and increase awareness of their

respective needs. The strengths perspective is also guiding current research. For example, Greenberg, Greenly, and Benedict (1994) studied the contributions of individuals with a mental illness to their families. They reported that contributions included companionship, assistance with household chores, and shopping.

Despite these benchmark improvements, families who provide care for an individual with a mental illness are still at risk of experiencing the effects of an unpredictable psychiatric decompensation. During periods of stability, the family may find solace in the possibility that their loved one is getting better, only to have this perception shattered as he or she re-enters acute psychiatric care. The money saved from deinstitutionalization has not been diverted to the families who provide care, thus creating for them an inescapable financial burden. Any services sought that are not covered by public assistance are at the families' expense.

Historically, providing direct services to families of people with a mental illness has not been a focal point in treatment plans. To counter this problem, families were encumbered with creating a service for themselves, by themselves. Thus emerged a new brand of self-help groups. According to Johnson (1990, p. 56), "For most people, the most significant advance in psychiatry in recent decades has been the growth of self-help and advocacy groups."

Today, families searching for self-help groups can turn to one of the 1,200 local and state affiliates of the NAMI for assistance. This non-profit organization also has a website<sup>1</sup> with a database of affiliates, links to self-help and support groups, and information on mental illness.

<sup>1</sup> Available online: <http://www.nami.org>

## TRADITIONAL SELF-HELP GROUPS

Save the occasional request for a donation to cover the cost of flyers and coffee, the groups are free of charge. The groups usually meet in the home of a participant, or space is provided by a school, community center or church. There is agreement among researchers and practitioners that participants experience a sense of catharsis when they are able to share their stories among others with similar experiences (Powell, 1987). There is also evidence that social support provided in self-help groups can help a person cope with stress (Medvene & Krauss, 1989; Potasznik & Nelson, 1984). From a practical standpoint, participants learn coping strategies from each other (Potasznik & Nelson, 1984) and veterans of the mental health system can offer guidance to newcomers. Participants in self-help groups also become aware of professional services from others and are likely to seek them out (Powell, 1987). Self-help groups for families of people with a mental illness have even transformed into successful lobbying groups (Jacobs & Goodman, 1989).

Self-help groups are not the perfect solution, however. Some communities do not have self-help groups, especially in rural areas where there is a shortage or scarcity of resources. Where groups do exist, families may not attend for various reasons. Poorly run or unorganized groups can give a family the impression that self-help groups are a waste of time. Some families refuse to attend following a bad experience such as a breach of confidentiality by another group member. During periods when families need the most help—for example, a psychotic episode—the family may be unable to attend the group due to disrupted sleep and work schedules.

## ONLINE SELF-HELP GROUPS

Since its advent in 1967, the Internet has experienced a metamorphosis from a network of computer resources for military personnel to a virtual library, shopping mall, video arcade, news station, and communication center, available to anybody with a personal computer, modem, and an Internet service provider. During this transformation, online groups—also referred to as e-groups, forums, listservs, bulletin boards, and mail groups—have quietly woven themselves into the Internet community and become a ubiquitous resource for almost every medical, psychological, and social problem.

According to Galegher, Sproull, and Kiesler (1998), there are over 200 Usenet groups devoted to conditions or situations that cause distress, and over 125 of these groups are for support. Liszt, a website that indexes listservs, contains over 500 groups on health related topics. Another popular website, Yahoo!, allows users to start and manage their own electronic group. On this site there are over 500 electronic groups related to mental health. These data suggest online groups may be the next major advance in services for families of people with a mental illness.

Online groups have a variety of formats. In public (open) groups, people can freely join the group, post messages and search the archive without any restrictions. A private (closed) group requires an application to the owner of the group. Synchronous communication is a live interface with another person or group of people via the Internet, which is achieved through the use of an Internet site supporting this communication or special communication software. Asynchronous communication is more popular than synchronous communication, using e-mail, or a bulletin

board as the means of communication. Participants in an asynchronous group can read and respond to messages at their convenience. Discussions can also develop by threading messages—that is, placing a brief descriptor of the message in the message's subject line for group members to review the subject lines and choose the messages of interest. When a member responds to a posted message, the response is automatically grouped with the initial message in the thread.

The same helping techniques found in face-to-face self-help groups are also found in online groups (Finn & Lavitt, 1994; Salem, Bogar & Reid, 1997; Winzelberg, 1997). Because of the inability to include paralinguistics in the written message, it seems that emotional support and empathy would be compromised in online groups. However, Salem, Bogar, and Reid (1997) studied an online group for people with depression and reported that, in comparison to face-to-face groups, online participants engaged in higher rates of emotional support and self-disclosure. Finn (1999) isolated 14 categories of helping mechanisms in a study of an online group for people with physical disabilities. The majority of the discussion in this group—21.2% of 718 messages—engaged in socio-emotional exchanges (for example, providing support and empathy). Finn and Lavitt (1994) studied an online group for sexual abuse survivors. Although the online participants were able to offer the same help that is found in face-to-face groups, they were less knowledgeable in working through the trauma. White (2000) reported on an online group for caregivers of Alzheimer's patients, and the greatest numbers of postings were from participants who sought or provided information.

As users become more experienced with online groups, they will likely encounter shortcuts, abbreviations or other unique

ways of communicating emotions. For example, the characters LOL and GOK mean laughing out loud and god only knows, respectively. And typing in all capital letters indicates a yelling or very loud voice. A variety of smiling and frowning faces created with different strings of characters are also common. Kurtz (1997) offers a practical listing of ways of communicating emotions on the Internet.

The same problems and difficulties that are barriers to successful face-to-face groups are also present in online groups. Shulman (1994) postulates four phases of group development: preliminary, beginning, work, and ending/transition. When a new member joins, the group returns to the beginning phase of development to clarify roles and define purpose. Open online groups, like face-to-face groups, may not be productive or fail to spend meaningful time in the work phase with the continual introduction of new members. Some online groups have members joining and dropping out on a daily basis. These groups are at risk of never reaching the work or ending/transition phases. Other problems include attrition, negative statements, discussion unrelated to the purpose of the group, inappropriate disclosure, and unbalanced communication among participants.

#### PURPOSE OF THIS STUDY

According to Jacobs and Goodman (1989), research on self-help groups that address major mental disorders is rare. The purpose of this study, therefore, is to increase and expand the current research base. This is also the first study that examines an online self-help group for caregivers of people with a mental illness. The following three questions guided the development of this research. First, how are self-help mechanisms used in the communication

of participants of an online group for caregivers of people with a mental illness? Second, what is the frequency of self-help mechanisms? And third, what patterns of content emerge within the messages of the group?

#### METHOD

This is a case study of an online self-help group for caregivers of people with a mental illness. It is an open group and does not have a moderator. On the group's registration web page, it advertises itself as follows: "For people with a family member with schizophrenia and related mental health problems. It helps to talk over the things that happen to a family when one of their precious family contracts this insidious illness and talking to someone who understands, certainly helps."

The group is asynchronous, utilizing a bulletin board and e-mail to exchange communication. To post a message requires free registration with the group, which also allows the participant the convenience of posting and responding to messages via e-mail. Anybody can view the messages that are on the bulletin board or in the archive.

#### Ethical Considerations

There has been previous discussion regarding the ethics of Internet research (Finn, 1999; Salem, Bogar, & Reid, 1997; Winzelberg, 1997). To date, however, researchers have not agreed upon a common set of guidelines for Internet research. This research followed the same ethical guidelines that governed the work of Finn (1999). Informed consent was not obtained, as the messages were available in a public Internet archive without any restrictions to access. Additionally, many participants did not disclose their e-mail address; thus requesting informed consent was not possible. For protection of identity, the

name of the group is not provided, pseudonyms are used in place of actual names, and the examples of messages have been altered so the participants would not recognize their messages.

### Coding

Two coding systems were developed for this study. The first system coded for self-help mechanisms contained in the written messages (see Appendix A). Self-help mechanisms are the parts of messages that facilitate the development of supportive or helping relationships among participants of self-help groups. Messages outside of the observation period for this group were used to test various code systems used in previous analyses of online self-help groups (Beals, 1992; Finn, 1999; Salem, Bogar, & Reid, 1997; White & Dorman 2000; Winzelberg, 1997). Ten categories from a combination of the systems were selected based on their discrimination and relevance to this online group. Each message received one code based on its primary focus (Finn, 1999).

Three categories from the self-help mechanisms code system required content that directly or indirectly related to mental illnesses: disclosure, provide information or advice, and request information or advice. Messages that received one of these codes were reviewed, and a code system of 16 categories for content was developed (see Appendix B). These messages were coded, and each message could receive multiple codes based on the content of each category. To receive a code or multiple codes, the content of the message had to meet two criteria. First, the content must relate to the participant or the individual with the mental illness. Second, the content must be germane to issues of mental illnesses. For example, the content of the following message was coded for medications (see Appendix B), but the content regarding computer difficulty was disregarded: "I am having difficulty with

**Table 1—Frequency and Percentage of Messages in Each Self-Help Category**

CATEGORY	FREQUENCY ( <i>N</i> = 417)	%
Disclosure	160	38.6
Provide information or advice	89	21.3
Empathy or support	73	17.5
Gratitude	22	5.2
Request information or advice	22	5.2
Computer issues	19	4.5
Friendship	17	4.0
Creative expression	13	3.1
Structure	1	.2
Negative statements	1	.2

my computer and cannot seem to change the font. Anyway, does anybody know anything about the side-effects of Zyprexa?"

The author coded all the data. To establish reliability, 30 messages were randomly selected and coded by a Master's level social worker. An agreement of .81 and .87 was established for the self-help mechanism and content code system, respectively.

## RESULTS

### Sample

All messages (*N* = 430) contained within an 18-month observation period were downloaded. Five duplicate messages and eight messages that did not contain content were removed from the sample, leaving 417 usable messages. Thirty-three people participated in the group during this period. The average number of postings for each participant was 12.6

and the range was one to 92. Although 33 people posted messages to the group, 16 posted just one or two messages, indicating a small cadre of active participants.

The gender of the participants was ascertained by reviewing their online profiles and handles. Six men and 26 women participated; the gender of one participant is unknown. The average number of messages posted by men was 1.8 (*N* = 11); for women, the average was 15.5 (*N* = 405). The participant whose gender was not identified posted one message.

All but four participants lived in the United States; the others lived in the UK, Peru, Australia, and Canada. The messages were all written in English. It was not possible to determine the number of "lurkers"—people who read the messages but did not participate by writing messages.

**Table 2—Frequency and Distribution of Content by Self-Help Category**

CONTENT AREAS	TOTAL		DISCLOSURE		PIA <sup>1</sup>		RIA <sup>2</sup>	
	N	%	N	%	N	%	N	%
Emotions	114	42.0	99	61.8	13	14.6	2	9.0
Diagnoses	94	34.6	54	33.7	30	33.7	10	45.4
Symptoms	85	31.3	49	30.6	29	32.5	7	31.8
Medications	79	29.1	53	33.1	20	22.4	6	27.2
Treatment	72	26.5	59	36.8	11	12.3	2	9.0
Social Network	60	22.1	47	29.3	10	11.2	3	13.6
Professionals	50	18.4	39	24.3	10	11.2	1	4.5
Legal	49	18.0	38	23.7	10	11.2	1	4.4
Personal	45	16.6	21	13.1	18	20.2	6	27.2
Resources	31	11.4	10	6.2	19	21.3	2	9.0
Financial	30	11.0	24	15.0	4	18.1	2	9.0
History	21	7.7	13	8.1	6	6.7	2	9.0
Housing	18	6.6	18	11.2	-	-	-	-
Substance Use	14	5.1	10	6.2	3	3.3	1	4.5
Social Perceptions	11	4.0	7	4.3	4	4.4	-	-
Vocational	7	2.5	5	3.1	2	2.2	-	-

<sup>1</sup> PIA: Provide information or advice

<sup>2</sup> RIA: Request information or advice

Table 1 is a summary of the frequency and percentage of messages in each self-help category. Table 2 is a summary of the frequency and percentage of content by self-help category. Because each message could receive multiple codes for content areas, the totals do not add up to 100%.

### Discourse Analysis

**Disclosure.** The most common type of self-help mechanism in this group was disclosure ( $N = 160$ ). The most active participants wrote updates of their lives, describing events as they relate to their experience of a family member or friend

with mental illness. New participants to the group commonly wrote an introduction of themselves, their relation to the person with a mental illness, and the difficulties they are facing. In the content analysis, it was found that 61.87% of these messages contained discussion of emotions. Participants appeared to write about emotions to achieve a sense of catharsis, as they were able to immediately share their experiences following a difficult event among a group of people with similar experiences. The following was excerpted from a long message illustrating this point:

How I despise this roller coaster!!! I fight depression and have all my life, and now I have to deal with a schizophrenic child. You are all very accurate in your descriptions of this horrific illness. To give and give and receive nothing in return hurts so bad. This is not easy to cope with. It helps to say this and hear from others with similar experience.

In messages of disclosure, participants also discussed issues of treatment ( $N = 59$ ), diagnosis ( $N = 54$ ), medications ( $N = 53$ ), and symptoms ( $N = 49$ ). Social

views and vocational issues were the least commonly discussed topics.

*Provide information or advice.*

Messages with a focus of providing information or advice comprised 21.3% of all the messages. These were both solicited and unsolicited messages, including suggestions on solving problems, sharing of resources found on other Internet sites, recommendations for books, and offering knowledge gained through personal experience.

There were not any participants who presented themselves as mental health professionals (for instance, psychologists, social workers, psychiatrists, etc.). Providing information and advice messages were also coded for content. Symptoms of mental illnesses and diagnoses were the most frequent content areas—32.58% and 33.7%, respectively. The following example illustrates this message type:

Hi Dana, that sounds frightening. Have you taken him to a pediatrician and told him or her what is occurring? I don't know whether or not it is possible for a three-year-old to have schizophrenia, but it is not silly to be concerned. You should ask your doctor . . .

*Empathy or support.* This was the third most frequent type of self-help mechanism among the messages (17.5%). Many difficulties described by the participants did not have an immediate or clear solution, but participants were able to recognize common experiences and offer words of hope and encouragement:

Hi Martha, that is tough; I know how worried you are. I wish I had some answers for you. Just keep hanging on. Take care of yourself, which I know is hard to do when we are so worried about our loved one, but we need to be well so we'll be there for them. Joanne.

*Request information or advice.* There were 22 messages (5.2%) that were requests for information or advice. For each request, there was an average of 2.04 responses ( $SD = 1.82$ ); three requests did not receive any responses. Forty-five percent of the messages contained requests for information or advice about diagnosis. These were usually from new members with little experience with mental health diagnoses. This segment of participants sought to expand their knowledge of a specific diagnosis in an attempt to better understand the illness of a family member or friend. The following was a message posted by a woman whose son recently began hearing voices: "I am wondering what does it mean to have schizophrenia. If you hear voices does that mean you are schizophrenic? Can people without schizophrenia also hear voices?"

*Gratitude.* Only 5.2% of the messages were coded as gratitude. Messages of gratitude were found directed toward specific participants or to the entire group. These were usually in response to previous messages that provided information or advice or messages of empathy or support. Saying thank you or indicating an appreciation of responses were typical forms of gratitude.

*Computer issues.* There were 19 total messages that received this code. This category did not address mental illnesses but was necessary for maintenance of the group and kept participants with less-developed computer skills connected. Participants sometimes sent test messages to discern whether or not the messages were being posted. Others sent updates of new e-mail addresses.

*Friendship.* Messages of friendship occurred in 4% of the messages. Similar to computer issues, these messages did not explicitly address or relate to issues of mental illnesses. However, they made the online environment more personal. Electronic greeting cards or messages

during the holiday seasons were the most common types of friendship messages. Some participants sent jokes or funny stories intended to lighten the discussions during stressful periods.

*Creative expression.* All of the messages coded as creative expression ( $N = 13$ ) were written by one participant. These messages pertained to mental illness and were written in the form of stories with specific attention given to dialogue and use of metaphor. Participants responded favorably to these messages, for the messages focused not only on the difficulties associated with mental illnesses but the rewards that can emerge from a care-giving relationship.

*Structure.* With 33 people posting messages, only one message had a focus of addressing the structure of the group. Because the number of active participants in this group was small, these messages were not a predominant feature.

*Negative statements.* Only one message received this code and it did not appear to disrupt the regular communication of the group. Participants did not comment on or reply to this message.

## DISCUSSION

Like traditional face-to-face groups, this group utilized a variety of self-help mechanisms and relied on the development of relationships as a foundation of support. The group provided an opportunity for family and friends of the people with mental illness to describe their lives, tell about traumatic events, and share emotions. Besides achieving a sense of catharsis through writing, the participants were able to offer and receive support within a community of people with similar experiences.

A feature unique to online groups, and an important aspect of this group, was

the immediate opportunity participants had to express themselves. Although participants had to wait for others to respond to their posting, the process of writing immediately after an emotionally charged event was described as therapeutic. Online groups also allow for a greater flexibility in regard to time commitment. Participants can read and respond at their convenience and have the freedom to focus on messages of interest to them, even focusing exclusively on responses to their own messages. These features are not feasible in face-to-face groups. It is not known whether or not this type of selective participation is detrimental to online groups.

Many new participants prefaced their introductions with the fact that they had been lurking for a while. This introduced the participants to the norms and the issues typically discussed among group members. Lurking may reduce the attrition rate of participants. Because attrition can detrimentally affect traditional face-to-face groups, it is also important to understand the effects of attrition among online groups. Nearly half of the participants in this online group wrote only one or two messages within the 18-month observation period. It is not known whether or not these participants continued to lurk among the group or quit.

This online group also differed from traditional face-to-face groups. Discussion of community resources—for example, vocational opportunities, housing, and local treatment options—was uncommon. This may be due to the fact that the online participants were spread across the United States and four foreign countries, thus making discussion of local resources impractical. An online group where participants live in the same city or county may overcome this limitation.

Spontaneous discussion seems less likely to occur in online groups. Because

feedback cues and non-verbal language are nearly impossible to communicate online, participants in online groups are encumbered with constructing clear, concrete messages. Therefore, certain processes such as brainstorming and expression of emotion are more effectively managed in face-to-face groups. These features were not present in this group or a significant part of other online groups previously studied.

Because this is a case study, the data presented in this report cannot be generalized to other online self-help groups. Additionally, the participants of this group may not be representative of participants in other online or face-to-face groups. Additional research is needed to better understand the development of helping relationships that develop online. Qualitative approaches can provide insight into the online experience of participants and their feelings and attitudes toward the online community. Using a quasi-experimental approach, researchers can compare face-to-face and online groups using variables such as satisfaction and family burden.

Future research should also incorporate a focus on gender differences. Although the purpose of this research was not intended to address gender differences, the messages revealed that the majority of participants were mothers providing care for a son with a mental illness. The messages written by men constituted only 1.4% of total number of messages posted. This contrasts the results of an online group for people with depression reported by Salem, Bogar, and Reid (1997) where 273 men and 173 women participated, posting 940 and 707 messages, respectively. They surmised that gender differences might be explained by the fact that, of all the computer users, males constitute the largest portion. The gender differences recognized in this study of caregivers of people with a mental illness may be attributed to the

fact that the majority of caregiving is provided by women. Additional research is needed to discern why the majority of participants were more likely to be providing care for a son with a mental illness rather than a daughter, as the gender differences among people with a mental illness in this group do not reflect the rate or morbidity between males and females.

Online self-help groups appear to be a viable option of support for families and friends of people with a mental illness. Before mental health practitioners refer family and friends to online groups, practitioners should spend time lurking among a number of different groups to identify groups that discuss relevant issues, have established norms for sending and receiving messages, and accept new participants. Practitioners should also provide education to potential online participants on Internet etiquette, protection of personal identity, and ways in which the group may best meet their needs. Until more research is conducted, online groups ought to be considered a supplement to face-to-face groups unless these groups are unavailable within their community.

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## APPENDIX A

### Coding System for Analysis of Self-Help Mechanisms

1. Disclosure: Sharing personal experience, thoughts, feelings, and emotions that are directly related to the purpose of the group.
2. Provide information or advice: Giving another participant factual information, guidance, or advice in dealing with an issue or solving a problem.
3. Request information or advice: Requesting factual information, guidance, or advice for dealing with an issue or solving a problem.
4. Empathy or support: Provide statements of understanding acceptance and encouragement to other participants.
5. Gratitude: Messages that thank other participants for their support or information.
6. Friendship: Statements that recognize other members as friends or identification with the group. Sending electronic greeting cards to other members in recognition of holidays and birthdays.
7. Structure: Statements intended to clarify, facilitate, or guide the structure or process of the group.
8. Creative expression: Using poetry, prayer, or prose to offer a form of self-help directly related to the topic of the group.
9. Negative statements: Disrespectful or sarcastic statements directed to other participants in the group.
10. Computer issues: Technical issues related to the use of the online group, the bulletin board or Internet.

## APPENDIX B

### Coding System for Analysis of Content

1. Social network: People within the social network, such as family, friends, neighbors, co-workers, etc.
2. Emotions: Thoughts, feelings, and attitudes directly or indirectly related to the experience of mental illness.
3. Housing: Any change in housing status or living arrangements.
4. Financial: Issues of money or financial obligations.
5. Legal: Being victimized or perpetrating a crime; interactions with law enforcement or the legal system.
6. Medications: Psychiatric medications and ECT.
7. Professionals: Interactions with mental health professionals, such as psychologists, social workers, psychiatrists, and psychiatric nurses.
8. Diagnoses: Psychiatric diagnosis or diagnoses.
9. Substance Use: Use of alcohol, illicit drugs, or over the counter drugs.
10. History: Relevant social history.
11. Symptoms: Symptoms and behaviors of mental illness.
12. Personal: Identifying information, such as name, age, sex, location, etc.
13. Treatment: Community and state psychiatric treatment facilities, including acute and long-term care.
14. Vocational Issues: Work and supportive employment.
15. Resources: Information in print regarding mental illnesses; advocacy organizations and clearinghouses.
16. Social Perceptions: Ways in which society perceives people with a mental illness.