

Social Support in Online Healthcare Social Networking

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Abstract

Support groups play an important role in helping individuals cope with their health conditions by providing members with a network of information and social support. It is not well understood what types of support are exchanged in an online, unmoderated, peer-to-peer communication of patients and caregivers. We analyzed the informational and emotional support offered and requested among an alcoholism discussion group using qualitative content analysis. Members offered a wealth of information in the form of facts, advice, and personal stories. Emotional support was also prevalent among threads where it was not explicitly requested. Our results highlight how peers are supportive to one another by providing resources and encouragement. These findings bring insight to new support we could provide to patients for sharing information, such as health professionals developing intervention programs. This work is a piece of an ongoing project that identifies the communication patterns of patients in online support groups.

1. INTRODUCTION

Online social networks allow users to connect with each other by overcoming geographic and time boundaries. Patients or their caregivers often turn to the Internet to seek support (i.e. advice and words of wisdom, sharing experiences), especially those who lack local resources. e-patients increasingly use social networking platforms to teach each other about conditions and treatments. This will impact the traditional patient-doctor relationship, and could even create the basis for a more market-driven system where customers are able to make informed choices [18]. Knowing what e-patients are seeking from these websites can provide insight to health professionals designing intervention programs, or inform design of these communities.

An online community such as a social networking site is a place where registered users create profiles about themselves, upload photos, keep in touch with friends and make new friends with common interests [4]. Medhelp is one such free online health community that connects people with medical experts and others who have similar experiences. Each day, members visit MedHelp to receive the support they need from other patients like them, and to share their knowledge with others in need. The website features news, clinical trials, personalized tools and chat forums. It was founded in 1994 as a resource to help patients cope with their health conditions by connecting users with information resources. It now hosts over a million users and hundreds of patient communities that can communicate through forums, profiles or journals.

Online support communities sometimes supplement regular offline group meetings (e.g. for people recovering from alcohol abuse) because it can provide additional emotional support for participants in offline recovery programs [19]. [24] studied the

impact of participation in online and offline support groups on the perceived stress level and coping strategies of participants. He found that the more time people spend in an online group, the larger their online social network and the higher the satisfaction with the received support. [12][13] found that the Internet was a potentially powerful tool in motivating and assisting problematic drinkers due to its anonymity and accessibility, where participants may not feel the same stigma associated with participation in face to face intervention [15]. Peer communication can play a role in facilitating new health habits, such as quitting smoking [3].

Psychology and communication research on social support shows two forms: resources intended to assist stressed individual to solve or eliminate problems causing distress, and emotional understanding to comfort support seekers [9][14]. Other types of positive interactions common among online support groups include introductions, expressions of gratitude or congratulations [7][10][11][21]. The first type, action-facilitating support, solves or eliminates problems facing support seekers by providing information or tangible support. Information resources include: offering advice, information referral, insight from personal experiences, or opinions **Error! Reference source not found.**[7][8][10][14][15]. Instrumental support includes offering financial assistance, services to relieve stress, active participation, or willingness to help [1][7][8][10][14][15]. Secondly, nurturant support comforts stressed individuals without direct efforts to solve problems causing the stress by making the recipient feel cared. Using verbal and nonverbal communication, giving compliments and recognizing achievement, and to help him/her have a sense of belonging among people with similar concerns [1][7][8][10][14][15]. Several studies have investigated social support exchanges in electronic environments for different patient communities such as breast cancer [8], disabilities [5], HIV/Aids [10], eating disorders [15], psychosis [7], and depression [21]. In this work, we look at the same range of informational, emotional and instrumental support in an online alcoholism community.

Moderators can be beneficial members of an online community [11]. In their study, they analyzed activity over a nine-month period on AlcoholHelpCenter.net, a moderated alcoholism community and found common themes in messages include (ordered from most to least): introductions, greetings, general supportive statements, suggested strategies, success stories, and discussion of difficulties. There were few extremely active users, but of the members who posted at least one message, over half were female. Their analysis examined types of messages rather than the prevalence support offered and sought. [6] conducted a qualitative content analysis of an online support group for smokers and concluded that the support group was mainly used as a source of support and encouragement during the initial phases of quitting cigarettes. Practical information and quitting tips were

less common, unlike in the alcoholism community where users were likely to describe why they decided to change habits [11].

The objective of this preliminary study is the first part of an ongoing project to use an unmoderated alcoholic community to understand the prevalence and characteristics of different support types (informational, instrumental, nurturant) that peers exchange in an online forum. This understanding can inform development of support for individuals to share experiences for overcoming alcoholism. Knowing characteristics of social support offered and sought in these virtual groups will help us to better understand the range of information needs (i.e. advice, sympathy) in a supportive environment. The contribution from such a study would provide greater insight into how alcoholics and their caretakers participate in online forums, or other means of communication. In the next phase of this ongoing project, we shall investigate the social supports in other channels such as journal and notes. We shall identify if the types of social support change when users of the same community interact through a different communication format. Although we select the alcoholism community in this study, we shall investigate if the types of social support change across different disease community in the future.

2. APPROACH

We chose the discussion board about alcoholism from MedHelp (www.medhelp.org) for this study. This study adopts a descriptive view to identify the different types of social support based on definitions given from relevant literature. A web crawler downloaded all the forum posts through 9th September 2009. There were 737 threads overall written by 454 individuals. A pilot study of threaded 493 forum messages was selected from a three-month period (9th June 2009 to 9th September 2009). This sample size of 493 messages is large enough to do a meaningful analysis. The sample is composed of 81 thread posts and 412 comments to the posts. Threads were initiated by 68 users. 97 users participated in posting comments. Some users had initiated threads and posted comments. A total of 128 participants had involved in the forum. The average number of comments per post is 5.08. The average number of participating users per thread is 4. The maximum number of participating users per thread is 12 and the median number of participating users per thread is 3.

The goal of this research was to find examples of social support as they occur in online communication. Qualitative content analysis was chosen since it deals with the interpretation of the codes. We followed an inductive approach to determine the different types of social support under categories: Informational, Nurturant, and Instrumental. In addition, we looked at interactions across several dimensions (offered vs. received support, post vs. comments). Offered support refers to the support that is given or expressed in the message, i.e. *you should see your doctor to address your condition*. Requested support refers to the type of support sought, such as *is there a medicine to take to stop the craving for alcoholic drink?* The threads are arranged by the website into the first post of a thread and the comments. The following figures show example of post and corresponding comments.

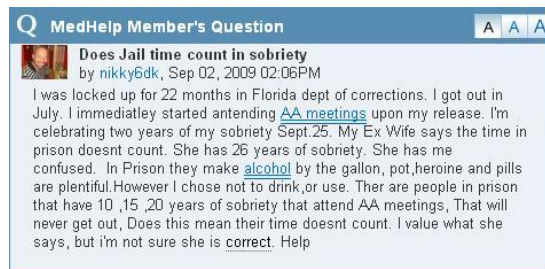


Figure 1 Example of MedHelp forum post

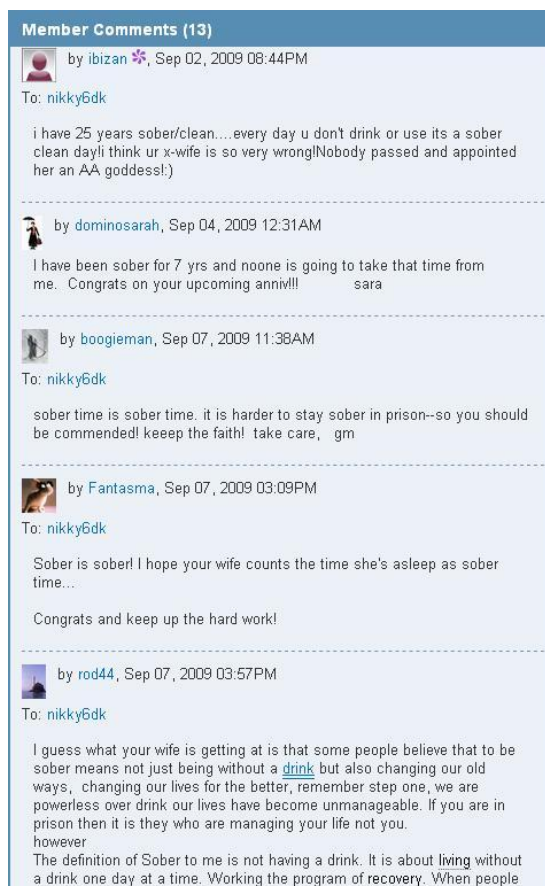


Figure 2 Example of MedHelp forum comments

Development of code scheme

Categories for coding were developed by reviewing existing samples and descriptions in related research studies, organized in the categories defined by [14]. These categories are appropriate for this study and they were also used in other studies of online support groups [5][7][10][15].

Analysis

We calculated the frequencies of each code category to analyze the overall levels of activity of each post (i.e., how many codes per message?) as well as the support categories. The most support, *Informational Support*, was further analyzed in sub types. We ignore typos and grammatical errors in messages.

Coding Scheme

There are 10 codes sorted into three categories. The categories are not exhaustive, in that some of the behaviors noted by literature did not match this data (e.g., instrumental support). Only those instances that fall into one of the 10 social support categories were tallied.

Informational Support: posts providing information on treatment, coping, etc. [1][7][8][10][14][15] Subcategories include:

Advice: Offers ideas and suggests actions, Provides detailed information, facts, or news about the situation or skills needed to deal with situation [14].

Example: “*Campral works better...ask u r doc about it!*”

Suggestions for course of action tell someone in order to improve the situation, such as speaking with a doctor or joining a face-to-face group.

Referral: Refers the recipient to some other source of help [14].

Example: “*Im gonna send you a link that might help.*”

This is directing someone to a resource such as book or website that contains related health information, rather than telling someone to take a course of action.

Fact: reassesses the situation and presents facts [14].

Example: “*Drinking too much alcohol daily can be a high risk to your health, you might fall into alcohol addiction.*”

This includes telling someone information that can be supported by evidence or unbiased observations.

Personal experiences: stories about person’s experiences [14]

Example: “*I have been going though something like that with an addict using in our bathroom and...*”

Personal experiences are different from facts in that it contains a personal nature, such as descriptions of specific events not medically related.

Feedback/Opinions: a view or judgment formed about something, not necessarily based on fact or knowledge [8].

Example: “*From what have you posted, it seems that you are in the stage where you have been looking to drink everyday and it is a clear sign of alcohol addiction.*”

This is different from advice because it does not provide a suggestion for action, but rather thoughts on a situation.

Nurturant Support: posts providing expressions of caring or concern. [1][7][8][10][14][15] Subcategories include:

Esteem: positive comments to praise support seekers abilities or to alleviate feelings of guilt [9][14].

Example: “*Congratulations on your sobriety!*”

Network: messages to broaden support seekers social network so they don’t feel alone [14].

Example: “*Just reach out and I will be there ok?*”

Emotional: providing understanding of situation, express sorrow, provide with hope and confidence [8][14].

Example: “*You’re going through a rough time...*” or “*Hang in there hon*”

Instrumental Support: provision of material or financial aid, or services. [1][7][10][14][15]. There are no examples available from the dataset. An example is offering to drive someone to Alcoholics Anonymous meeting.

3. RESULTS

Among the 81 threads in the sample, 56 postings were created by users seeking support for themselves; 14 by caretakers (of friends (3), family members (7), spouse (2), or by significant other (2)); and 11 unknown. There were 412 comments to these posts, which totals to 493 messages. Support is coded for both those offered and sought, and by first post of each thread and the comments.

Table 1. Summary of Offered Support

| | Posts | Comments | Combined |
|-------------|-----------|------------|------------|
| Information | 82.7 (67) | 85.2 (351) | 84.7(418) |
| Nurturant | 16.0 (13) | 66.9 (276) | 58.6 (289) |
| Instrument | 0.0 (0) | 0.0 (0) | 0.0 (0) |
| Sample Size | 81 | 412 | 493 |

Of the offered support, 67 posts out of 81, or 82.7%, were providing information. For instance, users introduced themselves by describing how much they drink or stories of how alcohol is disruptive to their lives. Users were less likely to start threads offering nurturant support (16%) such as spending time together. Some messages had instances of both information and emotional support. 85.2% of the comments offered information such as updates on a situation or answering questions in the posts. 66.9% of comments offer emotional support such as sympathy.

Table 2. Different types of support offered

| # offered | Posts | Comments | Combined |
|-----------|-------|----------|----------|
| 0 | 8 | 4 | 12 |
| 1 | 37 | 102 | 139 |
| 2 | 28 | 129 | 157 |
| 3 | 7 | 106 | 113 |
| 4+ | 1 | 71 | 72 |
| Sample | 81 | 412 | 493 |

8 posts and 4 comments did not offer any type of support. Most messages had one or two codes, while many messages multiple types of support, especially in the comments.

Table 3. Summary of Requested Support

| | Posts | Comments | Combined |
|-------------|-----------|-----------|------------|
| Information | 72.8 (59) | 15.5 (64) | 24.9 (123) |
| Nurturant | 44.4 (36) | 6.3 (26) | 15.0 (62) |
| Instrument | 0.0 (0) | 0.0 (0) | 0.0 (0) |
| Sample Size | 81 | 412 | 493 |

59 posts out of 81 (72.8%) sought information such as recommended drugs for treatment. 44.4% sought emotional support from the forum. Conversely, in the comments there were fewer instances of requested support. 15.5% sought informational support such as clarification and a minimal 6.3% were looking for emotional support or validation.

Table 4. Different types of support requested

| # requested | Posts | Comments | Combined |
|-------------|-------|----------|----------|
| 0 | 22 | 349 | 371 |
| 1 | 41 | 58 | 99 |
| 2 | 16 | 5 | 21 |
| 3 | 2 | 0 | 2 |
| Sample | 81 | 412 | 493 |

In the data, most of the messages requested minimal support. 22 posts and 349 comments did not request support. Few messages requested more than one type of support and that is more likely to occur in posts than comments.

Each message on average contains 2.57 support codes. This number includes both offered and requested support. The maximum number of codes per message is 10, except among 1st post of each thread, which had maximum of 6 codes. Some messages only offer support (i.e., *“Have you tried Naltrexone? It is supposed to help with the cravings there are other meds that can help with it too. If all else fails, make a picture of tea and pop some popcorn and hang out with him with your “drinkö”*), or only request support (i.e., *“Hi, is there a medicine to take to stop the craving for alcoholic drink?ö”*). Factual Information was the most frequent category of the code scheme, present in 31.2% of the messages. An example of this would be a statement describing consequences of being an alcoholic, *“Suboxone is not for alcoholics dear! it is primarily used for heroin and opiate addicts who have used heavily for a substantial length of time.”* or *“I’m 52, been drinking heavily since I was 27”*. This shows how important it is for members of this online community to exchange information related to their situation (e.g., how long they have been drinking or sober, how often they drink, use of medicine, etc). The information support was observed in over half the messages (59.0%), where Advice (12.3%), Personal Experiences (8.0%), and Fact (31.2%) occur most frequently. The categories esteem (5.6%) and network presence (3.3%) occurs least frequently.

Information support was the most frequently noted category in this data set, so we further analyzed the types of information exchanged in this forum. Within the information support category, the table below shows frequencies of offered and requested information support in messages. Other researchers have noticed that people often ask for opinions in addition to wanting factual information so we also noted the occurrence of opinions in this sample [2].

Table 5. Informational Support

| | Posts | | Comments | |
|----------|------------|------------|-------------|------------|
| | Offered | Requested | Offered | Requested |
| Advice | 0% (0) | 27.1% (22) | 32.5% (134) | 1.9% (8) |
| Referral | 0% (0) | 4.9% (4) | 4.9% (20) | 0% (0) |
| Fact | 74.0% (60) | 48.1% (39) | 64.8% (267) | 12.3% (51) |
| Personal | 33.3% (27) | 1.2% (1) | 18.7% (77) | 0.5% (2) |
| Opinion | 0% (0) | 16.0% (13) | 13.6% (56) | 1.7% (7) |

4. DISCUSSION

This paper describes the results from a preliminary study of an online alcoholism community. Content analysis coding scheme developed from literature organized into Cutrona & Suhr’s category system [14] show that users of this community are similar to other communities who offer and seek general informational and emotional support [7][8][10][15][21]. This seems logical since people participating in support groups want to improve their situation[23]. Our results support previous findings by similar studies using same support categories developed by [14] who found little or no instrumental support [10][15]. Other studies looking at online support communities using their own coding schemes also did not find instrumental support [8][11][21]. We observed no instrumental support in this study. This may be an

attribute of virtual environments, where users do not know each other and may be located at diverse geographic distance. When two people know each other well, such as in the case of a married couple, instrumental support is more likely to occur [14]. Some messages may contain very few codes when user goes off topic; this is consistent with previous findings [15].

Our findings support previous studies showing greater informational support than the other types [7][10][15]. Providing information may be a strategy of support seeking by self-disclosure [15]. Themes in messages emerged about sharing personal experiences such as success stories, discussion of difficulties and exchanging advice, and general supportive statements. One main difference between our study and that of [11] is that MedHelp is an unmoderated community while AlcoholHelpCenter.net uses moderators, whose role is to greet new members, give general encouragement or specific suggestions. In the MedHelp alcoholism community, several of the most active members stepped up to this role. [8] found that patients exchange expertise in the form of describing types of problems, what to expect in different situations, solving the problems, recommendations, personal stories, suggested approaches, or referrals to information resources. Our findings suggest that ex-alcoholics offering personal stories and suggestions have valuable insight to helping alcoholics. Empathic interactions in online communities include self-disclosure, community building, medical facts, technical issues, or off topic stories [21]. The presence of emotional support is influenced by the topic being discussed, presence of women, and presence of moderators [22]. The presence of greater informational than emotional support found in this online support group may be explained by the nature of health-related groups, which are more likely to be fact-based [16].

5. CONCLUSION

The objective of this study was to identify the various types of support present in an online alcoholism community. Peers of online alcoholism communities are likely to exchange information and emotional support, even without moderators for discussion. Information support centered on facts about alcoholism, such as treatment or medicines. The advice peers recommended and personal experience shared reflect patient expertise they have gained through their own alcoholic experience and offer a source for others to learn from similar situations. Overall, it appears that participating in an online discussion board is therapeutic and constructive for individuals with alcohol addiction.

These findings bring insight to the range of support that could be provided to individuals for disseminating information in intervention programs. For example, health professionals can target users who are likely to share information and train them to give the right information. Doing this kind of work can provide many opportunities for future research, for instance, threads could be grouped for improved online discussion forum browsing experience.

Learning about the nature of social support provides a tremendous opportunity to characterize the kinds of assistance that peers can provide. Studies such as ours provide a new view of patient communication that health professionals could utilize to reach out to the public. Future research could explore the motivations

behind postings and the actual effectiveness of these social supportive messages.

The MedHelp community includes other features for patients to interact with each other, such as journals and notes. Journals allow users to record their thoughts and feelings, just like a personal diary. Sharing is can be set to viewable by anyone, limited friends or private. Notes are a way for users to keep in touch with each other, such as congratulating or saying hello. They can be viewed by everyone, friends, or no one based on settings. In future work we will be analyzing social support types on these additional communication channels.

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