

# A Study of Informational Support Exchanges in MedHelp Alcoholism Community

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**Abstract.** E-patients searching for online health information may seek support from the peers in health social media platforms especially when they cannot find the relevant information from authoritative Web sites. Many health social media sites have different ‘architectural elements’ to support the user communication. We seek to understand the relationship between social support and Computer-Mediated Communication (CMC) formats by comparing the social support types exchanged across multiple CMC formats (forums, journals, and notes) within the same community using descriptive content analysis on three months of data from MedHelp Alcoholism support community to find informational support (i.e. advice, opinions, and personal experiences, etc.). Forums are used for asking general questions related to Alcoholism. Notes are used for maintaining relationships rather than the main source for seeking information. Journal comments are similar to notes, which might indicate that journal readers consider the author as a friend. These descriptive results suggest that users may be initially attracted to the community forums for information seeking yet continue to engage in the online community due to relationships strengthened through journal or note formats.

**Keywords:** health informatics, social media, social support, computer-mediated communication.

## 1 Introduction

The Internet is a useful tool for finding health information and also for connecting people. People go online for communicative or social reasons; often, e-patients want to access user-generated or “just-in-time someone-like-me” health information [10,12,21]. In recent years, e-patients are increasingly sharing their health information with social networks by gathering information and seeking support as they face important decisions [10]. Such websites include community websites using software for newsgroups, blogs, social networking sites or micro blogging. These e-patients that seek, share, and sometimes create information about health and wellness from these sites can often benefit from sharing their experiences, discussing medical information, and exchanging social support [10]. Peer social support is beneficial for

e-patients coping with difficult health conditions and increasing access to relevant information [15]. Previous research literature suggests that online communities become surrogate families of e-patients, where members share common problems, help each other toward mutual goals, and support each other through good times and bad [24]. Many users join online support groups for a sense of community with those who experienced similar situations because they are more likely to have the highly sought after compassion and experiential knowledge [24].

Online communities exist across many social web technologies (i.e. email lists, discussion boards, etc.), and most recently, social network sites (SNS). SNS enable users to find each other and build connections using profile pages and private and public communication tools to communicate [1, 3]. It is unique from previous text-based communication formats because of its emphasis on representing relationships between users and ‘architectural elements’ that encourage interpersonal relationships [18].

Studying the patterns of nurturing interactions within a support community will give useful insight into users’ communication patterns. These results could contribute to improving the design of online intervention programs by suggesting new software features to promote a supportive environment. For example, the treatment for alcoholism often consists of participation in support groups for social support component (AA) or in recent cases, online interventions [5].

Previous research demonstrates e-patients’ information needs beyond what their health professionals provide or technical support (i.e. medication reminders), most especially for social support in making healthcare decisions [24]. Previous findings about social support did not look specifically at the relationship between the CMC format and the behavior patterns of individuals participating within an online support group. We perceive that CMC enables interpersonal communication in a public environment; however users often conduct their conversations on this platform as if it were a private space [18,19,22].

Online support groups are a convenient place for health consumers to find conversations useful in guiding their healthcare decisions, by helping them find similar patients to talk with [13,24]. These self-help groups have a variety of social support types (informational, nurturant, instrumental). These sites are good sources for people such as alcoholics to gather information anonymously to avoid the stigma that comes from traditional face to face conversations. Social support exchanges can be thought of in economic terms. In a successful supportive interaction exchange, there will be a combination of someone offering and someone requesting support. People seek may ask for help when there is an information gap. With an architectural view, we see that the site design affects online transactions of social support exchanges [8,18]. Site design “promotes the development of particular culture or behaviors and identity presentation”, which may be found through studying interactions between users [8]. Convenient features allow users to form and maintain online network “friends”, where if one user invites another user to be friend and if accepted, a relationship is established on the website [1]. Friends can communicate through SNS in several ways, including private and public messaging systems [20].

The increasing socialization of online health information is a new phenomenon that could have untapped opportunities for future health services as people gather

online to converse about health issues, especially in health support communities [10]. We investigate patterns of informational support exchanged across different social media communication formats. By conducting this study, we hope to gain a better understanding of the link between site design and communication for an online health community.

## 2 Methods

We extracted data from MedHelp Alcoholism Community ([www.medhelp.com](http://www.medhelp.com)) using a web crawler and selected a 3-month period of discussion forums, user journals, and posts on users' profile pages called 'notes'. The messages in each sample were converted to spreadsheets for descriptive content analysis. Definitions for social support types were developed from reviewing examples in related literature and matching them with themes presented within our data [2,7,16,23]. Social support is generally the provision of psychological and tangible resources intended to benefit an individual's ability to cope with stress, such as information leading the subject to believe that he is cared [2,7,23]. Concepts and their definitions were drawn out and organized into three main categories (information, nurturant, instrumental), suggested by [7]. We chose these three categories because the categorization is most commonly used in related studies and also covers a wide range of support types. Only informational support and nurturant support were found in the data. The third type, instrumental support, is typically found in face to face interactions and not found in the data for this study. In this paper we only report findings of informational support.

MedHelp is a health-oriented SNS platform with peer support communities helping individuals connect with people and to information resources. It is open for any registered user to join. There are several interpersonal communication tools, including discussion forums, journals, and notes. The three CMC formats investigated in this study are available for any MedHelp community member to post content, where each varies in features. Users can post questions or polls to the forum. They are required to fill out a title, select a topic, describe their question, and are free to add tags. Posting to journals can optionally include title, entry, tags, photos, with selected privacy options per post. A journal thread must be initiated by the profile page owner. Posting notes on a user's profile includes type of note and the content in the note. A note can only be posted by the users who have access to the profile page but the owner of the profile page cannot make a note to herself. If the user is not a friend, there is an option to befriend the user.

While the messages on each of these CMC formats might be displayed publicly depending on privacy level settings (public, friends, private), the literature review suggests that social interactions on each may have different kinds of support. All forum content created by users is set to publicly accessible. However, MedHelp allows journals and notes to be set to one of three options: 'Everyone', 'Only my friends', 'Only Me'. New posts to the forum can be viewed on the forum page, which is also known as the support community page. Updates to public journals (new posts or new comments) are listed on the support community page under 'recent activity'

box. There is also a section that lists community members with links to their profile pages. Each profile page displays sections of the user’s activity on the communication tools. Unlike the forum messages, journal and note messages can only be viewed on the individual profile pages. Privacy settings may affect what can be viewed on a user’s profile page. If the setting for journal and notes are set to ‘only my friends’ then only users who are ‘friended’ may view these content. If setting is set to ‘only me, only the user can see their own content when logged in. The content in each is organized chronologically.

**Coding Scheme – Informational Support Types.** Information support describes messages that convey instructions, including (a) advice, (b) referrals to other sources of information, (c) situation appraisal, (d) stories of personal experience, and (e) opinions. Messages coded as information support often appeared as an attempt to reduce uncertainty for the message recipient [2,7].

Support Type	Definition
Advice	Offers ideas and suggests actions for coping with challenges such as detailed information facts or news about the situation or skills needed to deal with the situation. i.e. “...and i want to quit, but am not able to do so as my wife always gives me tensions , What should i do?”
Referral	Referral to information is when recipient asks for information sources, or it could be efforts to link the recipient with a source of expertise. i.e. “How can I get to the video link? Thanks so much.”
Facts or situation appraisal	Facts or situation appraisal is offered when someone reassesses the situation, often to provide a different way to look at things. i.e. “I have talked bout this b4.....PAWS....Post Acute Withdrawal Syndrome...comes from years of heavy drinking....takes a LONG time for the central nervous system to repair itself...”
Personal Experiences	Stories about a person’s experiences or incidents. It has a more story like form that is about self-disclosure and possibly personal information. i.e. “i have 25 years sober/clean....every day u don't drink or use its a sober clean day!i”
Opinions	Opinions are a form of feedback, which can be a view or judgment formed about something. It is not necessarily based on fact or knowledge. i.e. “Antabuse is cheap and has two side effects men hate...onion breath and erectile dysfunction ...”

### 3 Results

Our data contains three samples of user created messages from the discussion forums (n=493), the user journals (n=423), and from profile posts (n=1180). The messages in forums and journals were grouped into two types, *posts* (i.e. messages that start the thread) and *comments* to the post. There were 81 forum posts (FP) and 412 forum comments (FC). There were 88 journal posts (JP) and 335 journal comments (JC) and 1180 notes (N). We first identified five types of informational support in the samples that were both provided and requested. 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 "drink"), or only request support (i.e., "Hi, is there a medicine to take to stop the craving for alcoholic drink?").

The number of messages offering and requesting different types of informational support is given in Table 1 and Table 2, respectively.

**Table 1.** Percentage of messages with informational support types

	FP		FC		JP		JC		Notes	
	O (%)	R (%)	O (%)	R (%)	O (%)	R (%)	O (%)	R (%)	O (%)	R (%)
Advice	0.0	27.8	24.2	11.8	2.9	29.4	21.9	3.6	13.6	0.4
Referral	0.0	5.1	3.6	0.0	19.4	0	2.3	0	3.1	0.4
Fact	69.0	49.4	48.2	75.0	60.2	52.9	66.0	96.4	74.0	96.7
Personal	31.0	1.3	13.9	2.9	8.7	0	2.8	0	2.1	0.4
Opinion	0.0	16.5	10.1	10.3	8.7	17.6	7.0	0	7.2	2.1

Overall, fact was the most exchanged type of information across all samples. Notes and JC showed similar patterns of behaviors for both offered and requested. JP, FP, and FC showed similar patterns for requested informational support. The pattern appearing in notes was different from the other formats for the aspect of information sharing. In forum messages and journal posts, users were likely to request information types other than and in addition to fact; however, in the notes format users are more likely to exchange facts without mentioning stories or referrals. This is different in the longer messages of journals and forums, which contain the more stories, opinions, and advice.

There was a relationship between offered and requested support, for example, advice is offered in the comments, but not in posts. For all the samples, fact is exchanged the most. There were more offered than requested supports in notes, especially for exchanging fact, advice, and opinion. This could be an indication of using notes format for altruistic reasons. The high incidence of fact offered in JP suggests that users were documenting their thoughts. Perhaps they did not expect responses, unlike JC messages where requested fact is very high. JP requests opinion and advice along with fact, and JC offers these three types more than the other information types. In JP, personal experience and referrals not requested at all but referral and fact given in most messages, which can suggest that journals might be a place for sharing information. JP might also be a good place to seek advice, as comments offers advice. Perhaps users writing journal entries might have a close relationship where each party typically gives advice and opinions.

Although patterns in forum posts and forum comments seem correlated, it followed a slightly different relationship. FP messages offered personal stories, facts, or a combination of these two. The relationship between FP and FC messages can be characterized as polite and altruistic exchange, where more support is given than requested. Referral was given in some messages, possibly as a strategy to obtain advice, stories, and opinions, for example, because offering opinions may not be helpful in seeking advice from others. JP contains the highest percentage of messages of offering information referrals, despite forums having more messages. This might be because users are recording information they discover.

## 4 Discussion

Internet users join online health support communities (like those available on MedHelp.org) even while a plethora of alcohol and other health information is available on the Internet because they provide additional peer support. Because the members are not health professionals, the members are drawn to the a social place where participants share insights with each other as opposed to purely health information sites (e.g. WebMD), where users may experience difficulty in understanding the large quantity of information available. The added social components in support communities – where e-patients can have their questions answered, and hear other e-patients' experiences – provide more easily digestible information, for example advice about applying new lifestyle changes.

To the e-patient, the interactivity of an online community is different from perusing static information pages because of the added social component. Social media technology makes it easy to share and seek information from peers who have experienced similar situations and can offer targeted stories and practical advice [17,24]. Internet users may also want to use these websites to stay in touch with close friends and family [11,14]. A forum space is similar to a waiting room at the clinic, in that people know it is more public than the doctor's office. In terms of informational and emotional content exchanged in the community, users were selective in what they write and whom they interact with across the CMC formats. In the forums, it appeared that the space was used a Q&A forum, whereas on profile pages and journals the "personal nature" might explain their behavior for more emotional content. Environmental factors may play a role in shaping this behavior, however it is also possible that user perception of these environments alter their motives...

Our results slightly differ from related studies of the same type concerning the levels of support identified [2, 6,9,15]. First, this study collected data from different text-based communication formats (journal, notes) than previous studies (mailing lists, discussion boards). The architectural elements are different and can affect communication. Second, the members of the MedHelp community are allowed to and often communicate with each other across multiple CMC formats instead of just one (i.e. email lists). Features such as the profile page and journals are similar to providing rooms for people to talk about more specific things and have fewer interruptions, and this availability impacts the conversations on the communal areas to be more formal and the other areas to be less so.

The MedHelp communities have several communication formats, each used for a different purpose. Constructing an arena for people to talk (i.e. email list and bulletin boards) is good for group style but for more tailored communication between smaller groups (more focused topic) or between two individuals, the other formats are better suited. People will have different needs for participating in an online community, for example some members sought information, while others sought compassion and intimacy [4]. In addition, patients may go through waves of information needs [27]. Posting to the forum may be a different purpose than journal or notes, for example, one might disclose personal information as a strategy for finding tailored information or to document experiences.

A longitudinal view of social support exchange could help us better understand the why some users are more likely to offer support and others to request support. Users in online support groups go through a few phases of involvement (engagement, adoption, and diffusion) before they can become ‘big brothers’ to ‘newbies [25]. Their involvement with the support group depends on amount of positive feedback received over time [26]. In fact, our findings through the lens of these social theories can advise the development and use of CMC for health care in specific instances where prescribing specific software design features for online intervention programs. For example, in initial stages of health treatment e-patients can be directed towards forum space for general information. Later on, if this e-patient is paired with in a buddy system such as those in Alcoholics Anonymous the e-patient can be direct to the notes type of CMC to enhance the relationship building. Further work specifically targeting the relationship formation in this community would help us better understand the evidence for the social theories.

We find the CMC format impacts communication behaviors, notes are similar to journal comments, forum comments are similar to journal comments, but forum posts stand out as having different pattern than other formats. Because privacy can be controlled through notes and journals, they are more personal than the public forum. It is possible that the users did not find it necessary to use privacy controls in the more personal areas because it seems more private. In a physical setting, it is easy for one to perceive the relative privacy of the space. However, in an online environment, the amount of privacy is not as transparent. In this case, perhaps the MedHelp users do not assess the online setting as they would a physical face to face setting. In light of the content observed through this community (i.e. blackouts, possible violent episodes, etc), the online setting diminishes amount of stigma that would be present in face to face support.

## 5 Conclusion

In this study we compared supportive interactions across different software features of a health social networking site. We found that there are different types of information exchanged as social support, and each CMC format has a different combination of patterns. While people can obtain social support from existing offline social networks, participation in online support groups have added benefits such as coping with chronic health conditions. We identified different types of informational support in the MedHelp alcoholism community across three text-based CMC formats. Each format was used differently. Forums were used for asking and sharing information with a wider audience. Journal comments were similar to notes with smaller groups of individuals interacting, which might be an indication that journal readers consider the author as a friend. Notes were not the main source for seeking information, but rather for maintaining relationships. Users joined the community seeking information however very likely remain active because of the community social connections presented.

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