

ORIGINAL ARTICLE

Online Social Support for Patients with Multiple Sclerosis: A Thematic Analysis of Messages Posted to a Virtual Support Community

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ABSTRACT

Background: Currently with the emergence of the Internet, patients have an opportunity to exchange social support online. However, little attention has been devoted to different dimensions of online social support exchanged in virtual support communities for patients with multiple sclerosis (MS).

Methods: To provide a rich insight, the aim of this qualitative study was to explore and categorize different dimensions of online social support in messages exchanged in a virtual support community for patients with MS. A total of 548 posted messages created during one year period were selected using purposive sampling to consider the maximum variation sampling. Prior-research-driven thematic analysis was then conducted. In this regard, we used the Cutruna and Suhr's coding system. The messages that could not be categorized with the used coding system were thematically analyzed to explore new additional social support themes.

Results: The results showed that various forms of social support including informational, emotional, network, esteem and tangible support were exchanged. Moreover, new additional social support themes including sharing personal experiences, sharing coping strategies and spiritual support emerged in this virtual support community.

Conclusion: The wide range of online social support exchanged in the virtual support community can be regarded as a supplementary source of social support for patients with MS. Future researches can examine online social support more comprehensively considering additional social support themes emerging in the present study.

KEYWORDS: Internet; Multiple sclerosis; Self-help groups; Social support

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INTRODUCTION

Multiple sclerosis (MS) is a complex neurological disorder caused by genetic and environmental factors as well as their interaction. Most patients with MS experience initial symptoms and signs during the ages of 20-40.¹ MS is the main cause of permanent and non-traumatic disability in young adults.² Despite previous studies and researches, its etiology still remains unknown.^{3,4} On the one hand, MS threatens the patients' independence and ability for effective participation in the society⁵ and, on the other hand, prognosis and its unpredictable phases immensely affect the quality of life and health of patients with MS.⁶

Supporting social ties and relationships between MS patients and others is crucial.⁷ Various studies have shown that perceived social support is an important source for patients with MS.⁸ It is shown to be positively associated with perceived physical and mental health status in MS patients.⁷ Social support is a mutual process characterized by a network of interpersonal relationships⁹ and improves the individual's ability to cope and provides them with psychological and instrumental resources.¹⁰ Among the important resources that empower the individuals by expanding their social network and increasing social support are the self-help groups.¹⁰ They have the potential to effectively promote the physical health and psychological wellbeing of patients.^{11,12}

With the emergence of the internet, social support may be exchanged over the Internet. The online phenomena known as "online social support" is a reciprocal process of support involving interpersonal relationships with mostly unknown others.⁹ Joining virtual communities can be an important source of online social support, as they function as self-help groups.¹⁰ Virtual communities have special benefits such as anonymity,⁹ 24-hour access, reasonable costs, and no geographical restriction,^{13,14} and may be more beneficial than face-to-face interaction.¹⁵

Several studies have analyzed forum

messages as a data source to explore the experiences of users particularly in relation to exchange of social support in online support groups. They have indicated that emotional and informational supports are among the most prominent types of social support provided in these virtual environments.¹⁵⁻¹⁹ In addition, social companionship is another facilitator offered even for inactive participants in these virtual communities.²⁰

Considering the movement restrictions related to MS^{21,22} and patients' limited ability to participate in support communities in actual space, virtual communities may be a potential venues for exchanging social support.¹² In Iran, factors such as the young population²³ and rising prevalence of MS to a medium-to-high risk level^{24,25} necessitate the use of virtual support communities by patients with MS. These patients are among the leading patient groups that have established and managed several virtual social support communities in Iran. Thus far, little attention has been devoted to different dimensions of online social support exchanged in virtual support communities for patients with MS and we know little about the member's experiences of online social support. This study aimed to explore different dimensions of online social support by utilizing a qualitative analysis of messages posted to a virtual support community for patients with MS.

MATERIALS AND METHODS

Selecting the Context of Study and Data Collection

The target group of this study was an online social support community for patients with MS which was selected based on several criteria. First, an online search was conducted that yielded two online social support communities for patients with MS. Then, the first author of the study joined these two communities and lastly "The MS Center Specialized Website" (<http://mscenter.ir/>) was selected for the study because of a longer history, more members and more volume and variety of message

activity. Launched and managed by patients with MS since 2009, “The specialized MS center website” is a Persian social networking website in Iran, with 10 discussion forums and 25 sub-forums on a variety of MS related topics. The members are often patients in different stages of the disease, but the patient’s family and friends and even patients with other diseases as well as non-patient individuals are the other members.

Data for this study were the messages posted to the virtual support community. There were 2452 threads comprising of more than 24520 messages posted from 20 March 2012 to 20 March 2013. Among them, 548 messages in 35 respective threads were selected using a purposive sampling approach to consider the maximum variation sampling based on the type of forum, sub-forum, discussed topics, and type of social support. This strategy allowed the messages which could provide rich insights into different dimensions of social support to be maximized and then analyzed and categorized as fertile exemplars. Moreover, this sampling technique was consistent with our data analysis approach (thematic analysis). Message sampling stopped when further data provided no new themes and data saturation had been achieved.

Data Analysis

A qualitative method with thematic analysis approach was used to examine whether various types of social support occurred among the members of the virtual support community. Thematic analysis was prior-research-driven. In this regard, the social support coding framework developed by Cutrona and Suhr (1992)²⁶ was used to categorize the social support in our data. We utilized this coding system as a sensitizing concept which proposed directions along which to look.²⁷

The coding system has been used and modified successfully in various studies in computer-mediated groups^{15,18,19,28} and it consists of 5 main categories and 23 subcategories. The main categories are informational support (providing information, realities, and advice

for reducing insecurities), emotional support (communicating love, concern, or empathy), tangible support (providing or suggesting physical and actual support for the patient such as services and goods), esteem support (emphasis on the qualifications and importance of the patient as an individual), and network support (connecting people with the same condition for expanding the patients’ social network).¹⁵ Using the coding framework accompanied by purposive sampling helped us effectively find new patterns of social support in our data originated from a virtual support community for Iranian patients with MS.

Coding Procedure

Firstly, the messages were preliminarily screened and selected based on the evidence of offering interest, belonging, respect and assistance to the recipient.²⁹ Next, the analysis was carried out according to the guidelines of Boyatzis (1998).³⁰ After implementing sampling and design issues (mentioned previously) in stage 1, we developed codes in the next stage and examined the applicability of the social support coding framework to our data set. During this stage, the sub-category of listening was deleted because it indicates simultaneous verbal communication between the listener and speaker¹⁵ and it is not possible through text communication in virtual space. Moreover, instead of the sub-category of physical affection that included physical contact such as hugging, kissing, and shaking hands,²⁶ the concept of “virtual affection” was used which is more suitable for virtual space.¹⁹ Finally, to determine the inter-rater reliability,³⁰ two coders (first and third author) coded about 107 (20%) messages separately. Using this, reliability of the coding procedure was confirmed as follows: informational support (75.5%), emotional support (78.9%), esteem support (72.7%), network support (63.6%), and tangible support (72.7%). In stage 3, we used the reviewed codes to validate them and interpret their meanings. In this regard, each message was read several times carefully and then coded for the presence of the social

support codes. The messages that could not be categorized with the adopted coding framework were analyzed thematically to explore new additional social support themes. Moreover, increasing the credibility of the results,^{13,31} each message was analyzed and coded in relation to the previous messages and respective thread.

Coding was performed using a special qualitative data analysis software called Atlas.ti. Data were transferred to Office Word files and saved in rich text format and then transferred into Atlas.ti (V6.0, Berlin, Germany).

Consideration of Rigor

Prolonged engagement with the data and selecting a reasonable volume of messages were among the most important measures taken for increasing the credibility of the study. Circular data collection and analysis resulted in rich samples with more variety. Using a comprehensive coding system (Cutrona and Suhr, 1992) reassured us that the analysis was being performed based on a theoretical foundation and using inter-rater reliability confirmed the process of analysis. The consistent process of coding and

recoding as well as external checking was among other strategies used for enhancing the confirmability of the results. Referring to the member’s profiles for coding the posts accurately also facilitated provision of the transferability criteria.

Ethical Considerations

This study was confirmed by the Human Research Ethics Committee of Shahid Sadoughi University of Medical Sciences (No: P/17/1/52321). Necessary coordination was made with the management team behind “The MS Center Specialized Website”. Moreover, we made an attempt to keep the message senders anonymous by not using their realnames.

RESULTS

In this section, the dimensions of online social support and additional social support themes explored and categorized in this study will be presented. Additionally, the final thematic map, showing five main categories and related subcategories, will be presented (Figure 1).

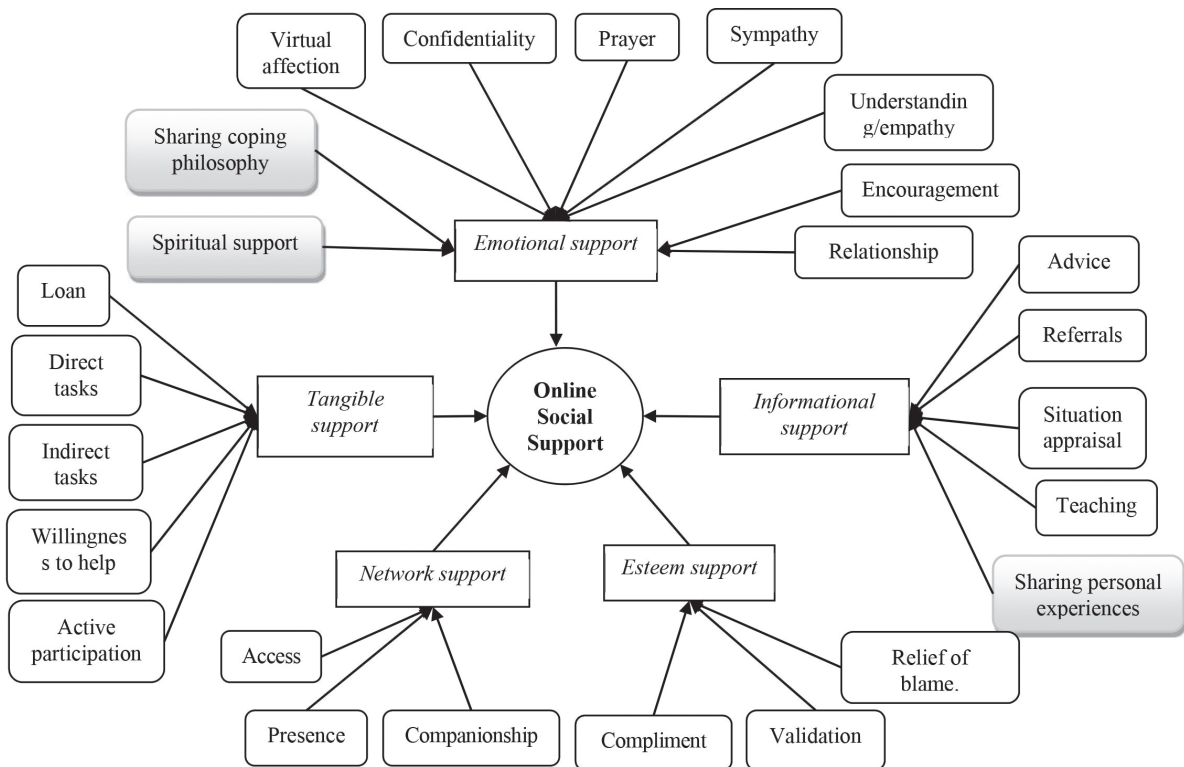


Figure 1: Final thematic map, showing main categories and related subcategories of online social support

Dimensions of Online Social Support in the Virtual Social Support Community of "MSCenter"

Informational Support

This category consisted of four sub-categories including advice, referrals, situation appraisal and teaching. The subcategory of advice included messages that provided specific advice or suggestions for coping with the personal or social challenges of MS or even other daily issues. In some cases, the advice was based on the scientific knowledge of the senders and sometimes it was based on their own experiences. For instance, in answer to someone with blurred vision who was worried, a member had replied:

"Don't worry Sahar, my mother had diplopia and she recovered. Don't be scared... each person has his/her own recovery period...I think it would be better if you listen to your doctor."

In referral messages, members tried to refer the patients to facilities or resources in the actual or virtual space so that they could cope with issues better. For example, posting the exact address of yoga classes was the example of referrals:

"Dear friends, you can find yoga classes and their address through this website: <http://bashgahi.ir/?cat=91>"

Situation appraisal messages were those in which the posters tried to clarify the patient's situation by using information or personal experiences so that he/she could make a more suitable decision. In answer to a member who had quitted his/her treatment process which the doctor has advised, another member had stated:

"I think the doctor's prescription was not wrong and ...and I suggest that you take one of the drugs your doctor had advised."

Teaching refers to messages that provide technical or factual information about various aspects related to MS and help the patients increase their level of knowledge and awareness:

"Dear friends...there is a specialized center for patients with MS at the hospital that does pulse therapy for free with insurance..."

for more information please contact these numbers ..."

Emotional Support

Emotional support was categorized into subcategories, including relationship, understanding and empathy, sympathy, virtual affection, prayer, encouragement and confidentiality. In messages containing relationship, the members tried to increase close and mutual group interaction in answer to his/her posted message by creating a friendly relationship with other members:

"I really want to come and meet all my friends outside the virtual space...but what can I do, it's impossible for me to take long trips... I am really eager to meet all you dear friends."

In messages containing understanding and empathy, the posters tried to explain similar experiences and tell other members that they are not alone and others have had similar experiences:

"Don't worry Fariba, my problems also began with pain in my eyes, blurred vision, and then actually losing my entire vision in my right eye...I also started with Prednisolone and was very worried about losing my eyesight forever...Don't stress yourself, and don't think about it. I regained my eyesight and I don't have any problems now, but it takes some time."

In messages containing sympathy, the poster expressed his/her sorrow and sadness for the patient's tensions and worries:

"I also express my condolences to your respected family and pray for those left behind."

Virtual affection was mostly expressed using emoticons. The following message was sent by one of the members of the virtual community to thank others. The poster expressed his/her emotions by using kissing emoticon at the end of the message:

"Hey guys, thanks for sharing the addresses and links"

In some instances, affection was expressed as text and using expressions such as *"I warmly shake your hands"*.

Praying was another form of emotional support for members in bad conditions:¹⁵

“My dear friend, I also have plaques in my neck besides those in my brain...I pray from the bottom of my heart for you not to have MS.”

Sometimes, praying emoticons were used for emotional support.

Moreover, members exchanged encouragement messages in difficult situations. These types of support were expressed in different formats such as message content, signature line, avatars, or even specific links. A graphic text of “fighting MS” in one member’s avatar was an example of promising messages which could encourage community members to overcome MS.

The subcategory of confidentiality (promising to keep the patient’s problem confidential) was found only in one message. This could be attributed to the anonymity observed in virtual spaces that greatly facilitates self-disclosure: *“By the way, I discovered something and I will tell you privately.”*

In general, using emoticons was an effective way for transferring emotions more objectively in this virtual community.

Esteem Support

Esteem support was examined using three subcategories: compliment, validation, and relief of blame. In compliment messages, members enhanced each other’s self-esteem by reminding each other’s capabilities:

“Dear Hamed, I like your efforts and perseverance...don’t you think we’re stronger than MS? I’m sure that you can overcome MS with your strong will, I hope you win”

Members also confirmed each other and shared similar views on a certain situation

First message: *“I am a new member; I only know that if we look at our illness like a normal on, we are half way through with our treatment”*

Second message: *“Same here, no worries.”*

Relief of blame consisted of messages that one member tried to persuade another member that he/she is not responsible for the

situation and that no guilt should be felt.

Network Support

Network support messages were observed in terms of three specific subcategories, including access, presence, and companionship. The primary function of these messages was to expand the social network.¹⁸

Access messages invited the members to participate in group discussions and activities and encouraged them to meet people with similar conditions, in actual or virtual space. The following was an invitation message sent by one of the managers of the virtual community for participating in group meeting in actual space:

“Those of you who are shy! Those that say they are shy in a crowd! Don’t worry, everything is under control, it’s safe and our forces have surrounded the enemy!”

The presence messages reminded the members that there is always someone there to listen to them and they can ask their questions. These messages ultimately conveyed a sense of worth to the members. In answer to a member who was worried about blurred vision, another member who did not live in Iran had replied:

“Hi, don’t worry or be stressed...because stress interferes with your body’s order. Try not to put too much pressure on your eyes. Tell us if anything new happens.”

Messages containing companionship not only emphasized the presence of members but also their companionship:¹⁸

“Hi dear friend, welcome to the website, I hope you get better, its better if you talk about your problem with other members...It could help you a lot and others can guide you.”

Tangible Support

Tangible support was examined using three subcategories of loan, direct task, and indirect task, as well as active participation. Suggesting loans or providing goods were supportive themes which was sometimes voluntarily offered by this community’s member:

“Three years ago that I started Rebif

injections, they gave me a device called Rebiject...in any case I only used it once. Now just text me if you have any problems with injections and I will send it to you ASAP."

Direct task could also be found in messages in which people send for doing a certain task in answer to other members' requests¹⁵. The nature of assistance was evident in this message:

"By the way, those who want to participate can leave a message for me so that I could register them".

Objective support such as indirect task could be seen when members helped each other in performing daily tasks related to work, education, and transportation and even household chores:

"I also want to say that those who want to come to Tehran from Karaj and don't have a car can come with me. I have room for three people."

Active participation was a suggestion for the audience to reduce their stress.²⁶ One member's suggestion for helping to hold a meeting in actual space was proof of such support.

The messages containing willingness to help depicted the sender's will for helping without showing what the exact nature of the assistance is.¹⁸ For example, one member used the expression "You can count on me for anything", to show his/her tendency for helping the music group of this virtual community.

Additional Social Support Themes

Sharing Personal Experiences

Most members shared their personal experiences about challenging with MS and its physical, psychological, and social consequences with two different approaches. The first was initiative and proposed voluntarily by more experienced members:

"I visited the doctor again after two months. He advised me not to wear myself out and avoid heat and stress. I also advise you to avoid becoming angry or exhausted because you might damage your optic nerve like me."

The second approach which was very common was to answer the members' questions using personal experiences. In

such cases, other supports such as advice and education were often proposed. Therefore, with respect to the nature of knowledge increase of this theme, we considered it as a subcategory of informational support.

Sharing Coping Philosophies

Very often, members shared wisdom, spiritual and even fatalistic philosophies in contents of their messages or signature lines. These shared concepts could stimulate a critical thinking in other members besides the emotional effects. We considered such messages as a subcategory of emotional support. For example:

"Wait patiently for time, everything happens in time. Even if the gardener saturates plants with water, they will not flourish in another season."

Spiritual Support

Messages implying spiritual support were those that increased hope in members by connecting them to a metaphysical source of power and were often entangled with other dimensions of support. With respect to the prominence of the emotional aspect of these messages, we considered it as a type of emotional support:

"I hate to see my dear friend worried for nothing...have faith in God and continue living a happy life...He would fix everything."

DISCUSSION

The aim of this study was to explore and categorize different dimensions of online social support in virtual support community for patients with MS. Data analysis showed that a wide range of social support was exchanged among the community members to help them cope with and confront mental, physical, and social challenges imposed by MS. Informational support was one of the most important categories in our study exchanged extensively among patients. This finding is consistent with those of previous studies^{18,19,32} and it seems that having access to informational

support is one of the main reasons for patients to join such communities. The high volume of sharing personal experience demonstrated its importance, especially for new members or patients with specific symptoms or drug side effects. Sharing personal experiences was one of the most prominent forms of social support among the community members and helps them manage their current situation better and have a more active role in confronting their illness.³³ On the other hand, knowing about other people's experience showed the members that they are not alone and such this issues are routine.²⁸

Exchanging emotional support was also prevalent among members and woven into other types of support. Since this type of support reduces the intensity of negative emotions,²⁶ it can be encouraging and soothing for members, persuading them to seek other needed support; it also could be a reason for patients to refer to virtual support communities.³⁴

Although esteem support was less exchanged with respect to informational and emotional supports, it seems that it could be vital for patients with MS because the manifestations and complications of MS could affect the patients' self image.⁷ Future studies can explore the outcome of joining virtual support communities such as coping with illness and accepting it and compare it with patients with MS that have not joined these communities.³⁵

The result showed that community members encouraged each other to participate in such support communities reminding the presence and companionship of supportive others and tried to expand their social network. These virtual support communities have a network context in which network connections created between members can potentially meet the needs of members to network support.^{15,19} Moreover, these structural connections can be a basis for provision of other types of online social support.

Sharing coping strategies was a common form of emotional support serving the members as a useful mechanism for better adjustment to illness and management of

challenges.³⁶ Similarly, men and women with breast and prostate cancer shared their coping philosophies as a type of emotional support in online Discussion Boards.³⁷

Spiritual support was an additional predominant support theme exchanged by the community members very often. This finding implies that virtual support communities can be regarded as unique settings for supporting the spiritual needs of patients with MS, because the restrictions caused by MS can lead to less attendance in religious communities in actual spaces.

In general, our message analysis showed that all five main categories introduced by Cutruna and Suhr (1992) and related subcategories except for listening were coded in the data. Therefore, the coding system could depict different dimensions of social support to a great extent in virtual support community for patients with MS. However, the findings revealed other new dimensions of online social support including sharing personal experiences, sharing coping philosophies, and spiritual support not included in the used coding system. It seems that these new dimensions of online social support have the potential to extend the used coding system and make it a more comprehensive framework for analysis of online social support.

There are, however, some possible limitations to the present study, which must be considered. Firstly, we exclusively studied a virtual support community for patients with MS, while virtual support communities for people with different diseases differ from each other.³¹ Secondly, the virtual support community we studied was as an Iranian one which could make some differences in findings. Additionally, analyzing only the messages could limit the generalizability of our findings,^{19,31} because it could not depict all outcomes of participating in such virtual communities. Other qualitative approaches such as in-depth interviews with members and quantitative methods including online surveys could provide complementary information.

CONCLUSION

The present study demonstrates that the virtual support community provides the patients with a unique opportunity to exchange informational, emotional, esteem support as well as tangible and network support. Additionally, the community offers an interactive space for sharing new social support themes including personal experiences, coping strategies and spiritual support.

Information retrieval, especially by sharing personal experiences can make the community a helpful resource for members, in particular for those with early detection of disease or new symptoms. Sharing coping strategies and spiritual support, in addition to other types of emotional support, represents the virtual community as a potential setting for the members to meet their mental and spiritual needs. Moreover, extending social network of members to new supportive resources seems to be an essential function of this community, as a platform, by which different dimensions of social support can be developed and reinforced virtually.

Overall, the results suggest that participation in virtual support community can empower the members to cope effectively with different disease challenges. Thus, virtual support community can be regarded as a supplementary source of social support for patients with MS and probably other chronic illnesses. Future research can examine online social support more comprehensively regarding additional social support themes which emerged in the present study. Also, measuring the impact of participation in virtual support communities on the health of patients is very crucial. Undertaking these researches can effectively help the health policy makers to find the best community based strategies for health promotion of patients with MS.

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