Internet Support Communities, Online Peer Support, Social Networks/Social Media & Internet Use by Hospitalized Patients

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Abstract

The purpose of this research was to explore internet support communities, online peer support, social networks/social media and internet use by hospitalized patients. Communication, relationships, education, language, and in general human connections through the internet are all important factors of how the World Wide Web is used. We investigated Internet support communities for people with health problems. More specifically, the objective of this study was to find out how people who have been hospitalized and are awaiting major surgery use the Internet to get educated about their situation and recovery. Results show that through the use of the Internet and online peer support, the participants received psychological support, hope, and guidance to recovery, while conclusions attribute this to feelings of reduced loneliness and increased understanding by people who have been through similar situations. Finally, the participants rated the internet and the online peer support that they received as extremely important.

Key Words: Online Peer Support, Social Networks, Social Media, Internet Use, Internet Support Communities, Hospitals, Patients.

1. Introduction

Nowadays people rely on the Internet for their information and communication activities. The advantages of getting educated through the Internet are vast and include reduced costs and access to a plethora of information. The Internet is currently a widely used medium for distance education (Taylor, 2002). It automatically integrates text, video, audio, animation, graphics and interactivity into a 24/7 globally accessed medium. Social media, social networks sites, email, bulletin boards, forums, chatting, dialogues, newsgroups, research, and interactive conferencing are all easily available with the Internet. "Learning that is supported by information and communications technologies" is also referred to as e-Learning (Ward, 2003).

Another important characteristic of the Internet is the opportunities it offers for human-human communication through computers and networks. As Metcalfe (1992) points out, communication is the internet's most important asset. Computer-Mediated Communication (CMC) has been in existence since 1969, and can be defined as "any communication patterns mediated through the computer" (Metz, 1994, pp. 32). December (1997, pp.1) defines CMC as "a process of human communication via computers, involving people, situated in particular contexts, engaging in processes to shape media for a variety of purposes." Studies of CMC can view this process from a variety of interdisciplinary theoretical perspectives by focusing on some combination of people, technology, processes, or effects. Some of these perspectives include the social, cognitive/psychological, linguistic, cultural, technical, or political aspects; and/or draw on fields such as human communication, rhetoric and composition, media studies, human-computer interaction, journalism, telecommunications, computer science, technical communication or information studies" (December, 2004, pp.1).

Through the use of CMC applications, online communities emerge. As Korzeny pointed out even as early as 1978, the new social communities that are built from CMC, are formed around interests and not physical proximity (Korzeny, 1978). CMC gives people around the world the opportunity to communicate with others who share their interests, as unpopular as these interests may be, which does not happen in the 'real' world where the smaller the interest in a particular scene is, the less likely it will exist. This is due mainly to the internet's connectivity and plethora of information available posted by anyone anywhere in the world.

The term online community is multidisciplinary in its nature, means different things to different people, and is slippery to define (Preece, 2000). The relevance of certain attributes in the descriptions of online communities, like the need to respect the feelings and property of others, is debated (Preece, 2000). Online communities are also referred to as cyber societies, cyber communities, web groups, virtual communities, web communities, virtual social networks and e-communities among several others.

In this study our aim was to investigate how people who are hospitalized use the internet for information and communication purposes. The paper continues with the background literature, the methods used and the results, and ends with the discussion and conclusions.

2. Background Literature

The Internet has changed the way we communicate (Laghos, Masoura, and Skordi, 2012) and get our information. Social media and social networking sites allow people to connect with each other and enable them to share their experiences, stories, and information using several media including text, audio and video.

As for communication, there are many reasons that bring people together in online groups. These include hobbies, ethnicity, education, beliefs and just about any other topic or area of interest. Wallace (1999) points out that meeting in online communities eliminates prejudging based on someone's appearance, and thus people with similar attitudes and ideas are attracted to each other. The Internet has an immense information base where people can go online and educate themselves on literally everything from learning languages (Laghos and Zaphiris, 2005) to gaining undergraduate and graduate University degrees.

In this study we look at how people use the Internet to access information and communicate with their peers to learn about their health conditions. A type of online interaction is peer support. "Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful" (Mead, Hilton & Curtis, 2001, pp140). When people find others that they feel are like them, they feel a connection and a deep understanding based on mutual experience (Mead et al, 2001).

Online peer support occurs through the use of Computer-Mediated-Communication, while web based communities are formed through people's Internet communication and interactions with one another (Laghos and Laghos, 2008). In the case of health reasons, peer support comes from people who experienced or are experiencing a similar life event and want to discuss and share their difficulties, information, experiences and mainly to support each other.

In a study regarding peer support for stroke survivors, the authors point out that peers provided emotional, informational and affirmational support. They provided validation, motivation, decreased feelings of being alone and encouragement to their peers. As for the peer supporters, through this process they had increased social connection, enjoyment and personal growth, and also experienced feelings of making a difference in the lives of others (Kessler, Egan and Kubina, 2014). Furthermore, in another study regarding participants' experiences of hospital-based peer support groups for stroke patents and carers, the authors reported benefits that included advice, new connections, helpful information and increased awareness of the condition (Morris and Morris, 2012). Our current study explores the use of the internet and peer support for people who have been hospitalized and will undergo major surgery. In the next section we provide a description of the methods used and the results obtained.

3. Methods and Results

Our study looked into the use of the internet, online peer support, social media and social networks by people who are hospitalized in order to undergo major surgeries. The study was carried out in private hospitals which are to remain anonymous as will the participants of the study due to privacy and anonymity reasons. Eleven participants took part in the study and were aged between 15-67 years old, both male and female.

The participants took part in an interview which was carried out face-to-face where they were asked questions regarding their use of the Internet to get educated about their condition and also their use of the Internet to communicate with their peers. Aspects studied included the devices they used, the ways that they would communicate with each other, the roles that they would undertake the types of support that they received, and how important they found this support.

Figure 1, shows the participants' responses to the question "How do you use the Internet to search for information regarding your condition and recovery". The participants were asked to name specific examples of the tools/websites they used and rate how much they used them. The scale used ranged from 1 (very little) to 5 (very much). The results show that the most important tool for finding information was Google with a rating of 4.91 out of 5. This was an expected result since most people's search engine of choice is Google. This was followed by Forums with 3.27, YouTube with 3.18, Facebook with 3.09 and Twitter with 1.09. It is not surprising that forums ranked this high, as the participants' noted, that ending up on forums was usually the result of their Google searches. The participants also stated that their use of YouTube was to view videos of their upcoming surgeries. Facebook also ranked quite high but they respondents noted that usually they could not find exactly what they were looking for. Finally, the results show that Twitter is not very helpful for the information they were searching for.
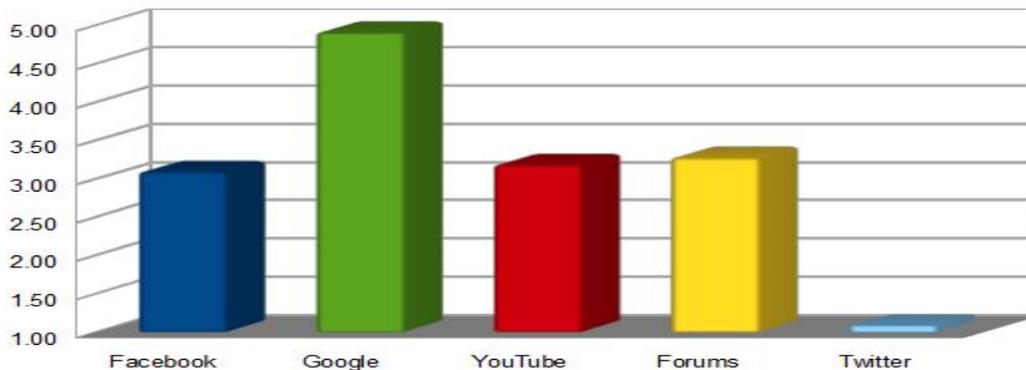

Figure 1 – How do you use the Internet to search for information regarding your condition and recovery

Figure 2, shows the participants' responses to the question "Which tools/websites do you use for peer support". The participants were asked to name specific examples of the tools/websites they used and rate how much they used them. The scale used ranged from 1 (very little) to 5 (very much). The results show that the most important tools for peer support were Facebook and Forums each with a rating of 4.82. The participants commented that the high rating of Facebook was due to specialized Facebook groups concerning their condition where they could meet and connect with people that have gone through similar experiences, while the high rating of Forums was due to the relevant discussions and helpful comments posted by their peers. YouTube received a rating of 3 due to the comment exchanges below the videos, while Google and Twitter each received ratings of 1.09 as they were not very helpful for peer support.
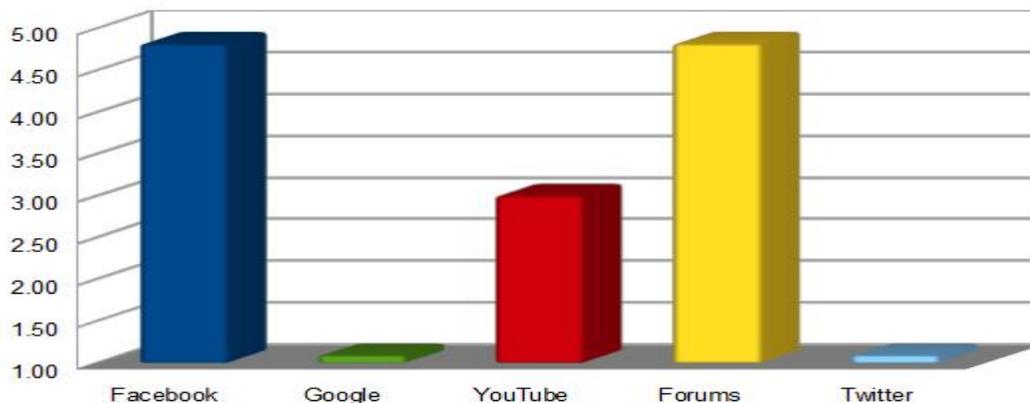

Figure 2 – Which tools/websites do you use for peer support

Figure 3, shows the participants' responses to the question "What ways do you use for real-time communication with each other". The tools/websites here differed from the responses of the first two questions since new apps were mentioned by the participants. Again the scale ranged from 1 (very little) to 5 (very much). The results show that all the tools mentioned were given high ratings: Viber with 4.82, Facebook messenger with 4.55, Whatsapp with 4, and Skype with 3.91. These results are not surprising, as the above apps are some of the most popular messaging and conferencing apps which include support for audio, video, and graphics. Moreover, in addition to peer support, these apps were the main ways that the participants would communicate with their family, friends and other loved ones. The respondents' noted that the slightly lower rating for Skype was because it seemed to drain their phone/tablet battery faster than the other apps.
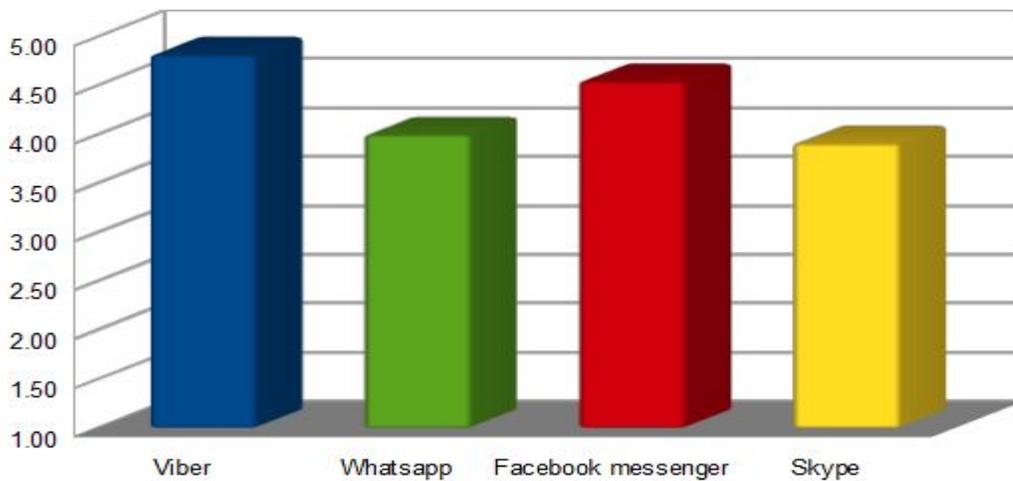

Figure 3 – What ways do you use for real-time communication with each other

As for the roles the participants would undertake, Figure 4 shows that they were mainly Information Receivers with a rating of 4.91. Information Providers was rated with a 2. This was another expected result since for many participants their health condition was sudden and they wanted to get informed about it. At this stage they were not educated enough to provide much information but stated that they would definitely be helping out their peers as well in the future.
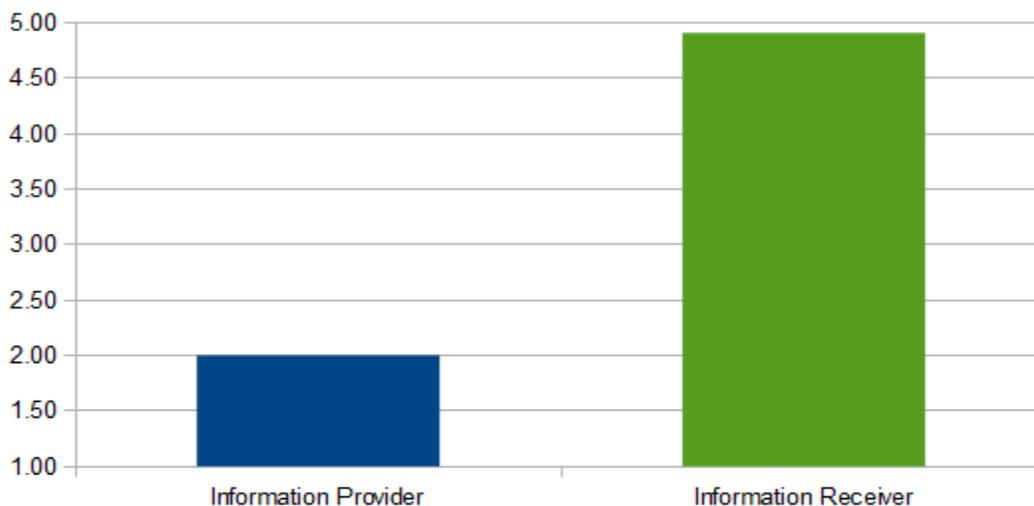

Figure 4 – Roles

Figure 5, shows the participants' responses to the question "What kinds of support do you receive from your peers". All factors were rated very highly by the participants. They would mainly receive psychological support and encouragement (each rated 5), followed by increased awareness of their condition (rated 4.91), motivation, information and advice (each rated 4), new connections (rated 3.91) and decreased feelings of loneliness (rated 3). All these factors show that peer support is crucial for the participants.
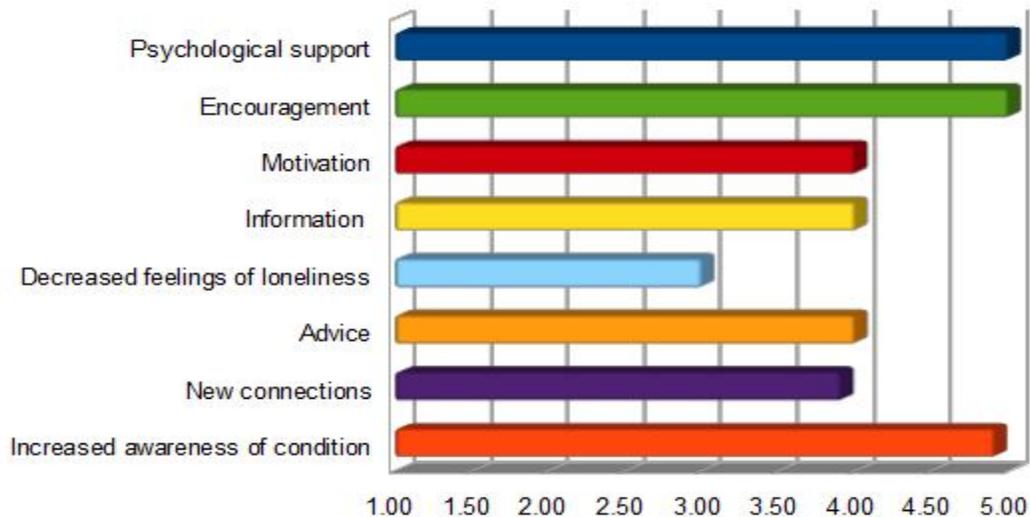
Figure 5 – What kinds of support do you receive from your peers

With regards to the devices they use to connect to the internet (Figure 6), mobile phones received the highest rating with 4.91, followed by tablets with 3 and laptops with 1.91. Desktop computers were not in the results since the participants did not have these in the hospital. The results do not come as a surprise, as all participants had their phones with them, while it can be seen that as the size of the device increased (i.e tablet then laptop), its use would drop since it was less of a convenience to have them in the hospitals.
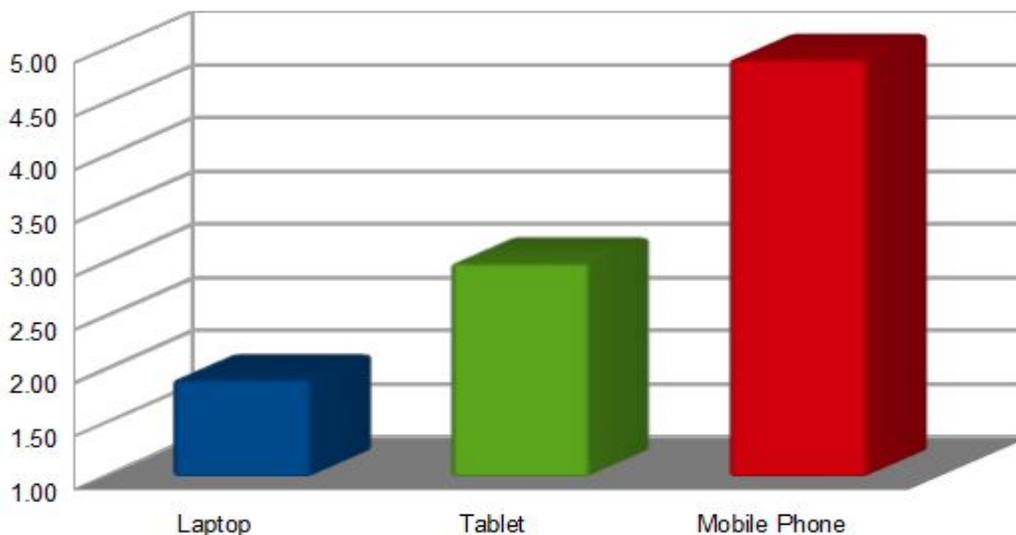

Figure 6 – Which devices do you use to connect to the internet

Finally, all the participants reported that the help they receive from the peers is extremely important to them and very much appreciated. It has increased their internet and social media use since they lie in bed waiting for the surgeries. It is a source of information and a pass-time. They note that the sharing of similar experiences, difficulties, exchanging of information, and support and guidance, provides them with the much needed hope that they are looking for.

4. Discussion and Conclusions

This study addressed internet support communities, online peer support, social networks/social media and internet use by hospitalized patients that will be undergoing major surgery. We analyzed their use of the internet to educate themselves about their health condition and recovery. Furthermore, we explored their use of social media and the support they are getting from their peers.

The results showed that the participants rely heavily on the use of the internet for their information and communication purposes. Through these, they receive psychological support, guidance to recovery and hope. Their peers help them reduce their feeling of loneliness and provide them with understanding as they have been through similar situations themselves. They would share their experiences, difficulties and relevant information and encourage each other to stay strong.

The participants themselves rate the internet and the online peer support that they received as extremely important. Based on all our findings we suggest that hospitals should provide all their patients with free wifi internet access as this is a crucial factor for their information, communication and psychological wellbeing. Nevertheless they should bare in mind some concerns expressed by doctors that medical information online may be confusing to patients, it may not be accurate, it may not be interpreted correctly, and patients may be affected by worst case scenarios related to their specific condition.

Acknowledgements

References

December, J. (1997). Notes on defining of computer-mediated communication. Computer-Mediated Communication Magazine, (3)1.

December, J. (2004), What is Computer-Mediated Communication. [Online] Available: http://www.december.com/john/study/cmc/what.html (August 8, 2005).

Metcalfe, B. (1992). Internet fogies to reminisce and argue at Interop Conference. InfoWorld.

Metz, J.M. (1994). Computer-mediated communication: literature review of a new context. IPCT, Interpersonal computing and technology: an electronic journal for the 21st century, 2(2), 31-49.

Kessler, D., Egan, M., and Kubina, L. (2014). Peer support for stroke survivors: a case study. BMC Health Services Research Journal. 14 (1), 1-9.

Korzenny, F. (1978). A theory of electronic propinquity: Mediated communication in organizations. Communication Research, 5, 3-23.

Laghos, A., & Laghos, S. (2008). Online Communication Networks & Learning Styles: Society, Technology and Education. In Web Based Communities 2008 Conference. Amsterdam, The Netherlands.

Laghos, A., Masoura, S., & Skordi, A. (2012). Linguistics in Social Networks. American International Journal of Contemporary Research, 2(1), 1-5.

Laghos, A., & Zaphiris, P. (2005). Computer assisted/aided language learning. Encyclopedia of Distance Learning, 1, 331-336.

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: a theoretical perspective. Psychiatric Rehabilitation Journal, 25, 134-141.

Morris, R., & Morris, P. (2012). Participants' experiences of hospital-based peer support groups for stroke patients and carers. Disability and rehabilitation, 34(4), 347-354.

Preece, J. (2000), Online Communities: Designing Usability, Supporting Sociability. John Wiley and Sons: Chichester, UK.

Taylor, R. (2002). An Introduction to e-Learning. Creative Learning Media. New York.

Wallace, P. (1999). The Psychology of the Internet. Cambridge: Cambridge University Press.

Ward, C. (2003). eLearning Training: Catching up with the Future. EDUCAUSE 2003 Conference. 6–9 May 2003, Adelaide, Australia.