Title:

Are online cancer communities able to provide important, necessary emotional support to cancer patients and their families?

Abstract

Online cancer communities provide important emotional and social support to cancer patients and their family and friends due to the fact that users can consult with others throughout the world, both in real time and asynchronously, from the comfort of their home, in order to discuss all aspects associated with their cancer while maintaining a level of privacy by remaining anonymous.

<u>Key Terms</u>*:* Community/Communities. Network. Health Issues. Support. Emotional Support. Online Support. Peer-to-Peer. Online. Cancer**.**

Patients with cancer and their families require support to assist them with their journey from diagnosis through to recovery or remission. Families and friends are unable to provide all the support necessary at this important time, the question asked in this paper is whether online cancer communities are able to provide a different type of support to supplement that available in face-to-face situations.

The family and friends of cancer patients do not always understand the stress that the patient is going through but a person who has been through the journey and survived can offer emotional support and provide insights into how to overcome their problems. The introduction of WEB 2.0 and its associated applications has allowed for "electronic peer to peer community venues" which has allowed cancer patients and their family and friends to come together with people from all around the globe to discuss their disease and offer each other "emotional support" (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Thus, online communities offer important support for cancer patients and their families by providing emotional and social support that is not available from the patient's family or friends.

A virtual community is "an aggregation of individuals or business partners who interact around a shared interest, where the interaction is at least partially supported and/or mediated by technology and guided by some protocols or norms" (Porter, 2015). This type of online community helps users gain access to necessary information that can be used for problem solving and decision making (Porter, 2015). An online cancer support community is one such virtual community. This coming together of people from all over the world and from different backgrounds enables a collective intelligence where information and support, plus links to other resources are shared (Malone, Laubacher, & Dellarocas, 2010). Wellman & Gulia, (1999) state that in an online community environment users are quite happy to help strangers, which might not occur in real life situations as "gender, age, race, ethnicity, life-style and socioeconomic status can influence the situation." They advise that information from a large group of people with weak ties, with differing backgrounds is more likely to be able to solve problems than a group of people who come from the same or similar backgrounds.

Another way online cancer support communities provide support to patients is by presenting ways to cope with stress. Wellman & Gulia (1999) are of the opinion that people using online communities are able to forge both weak and strong ties which can supplement those of family and friends. Namkoong, Shah & Gustafson (2017) suggest that beneficial family support is not enough, as the family of cancer patients, unless they have had the disease themselves do not understand the type of stress that the patient is under, but people who are suffering from the disease or who survived it are better able to understand what they are going through (p.1422). They also state that by becoming aware that others are suffering in the same way helps to promote both mental and physical health, as they realise they are not alone (Namkoong, Shah, & Gustafson, 2017).

In addition to realising that there are other people feeling the same emotions during their cancer experience patients also find that once they are diagnosed, they feel that

they have changed from the person they thought they were. Instead of being a husband or father, mother or sister, Harkin, Beaver, Dey & Choong (2015) found that cancer patients notice that they have become someone else after their cancer diagnosis. Cancer patients feel they are no longer who they thought they were but have become a 'person with cancer', a process which they termed "a journey to recreate identity". In addition to recreating themselves patients undertake several journeys during their cancer experience. "A journey to become informed" happens when users access online communities to gather information. A "journey through different worlds", is where users gain access to information whilst remaining anonymous. Harkin et al., (2015) found that most patients had to navigate their way through the aforementioned journeys during their cancer experience.

One of the advantages of an online cancer community is that interactions are not restricted to place and time, giving users the ability to interact with others all over the world at any time for asynchronous chat. They have access from the comfort of their home, rather than have to attend face-to-face groups which are sometimes scheduled at times and places which are difficult for patients and their families to attend (Harkin et al., 2015; Namkoong et al., 2017). Face-to-face groups have been set up to allow cancer patients to meet and discuss their disease and mechanisms for coping with cancer, depression and the stress associated with treatment and the recovery. These type of face-to-face interactions experience a large drop-out rate, as patients are unable to attend for various reasons, including: inability to attend the venue due to lack of transport, inability to drive and being reliant on family and friends for lifts, lack of available public transport, or meetings held at times when the patient is working, having treatment or when hospital appointments have been scheduled, all of which leaves the sufferer socially isolated (Harkin et al., 2015). Namkoong et al., (2017 p.1423) state that unlike a face-to-face situation where attendees may not want to discuss their personal situation, that online communities allow interaction where participants are not aware of another's real name, ethnicity or social status, where convenience and anonymity makes it easier to share sensitive information (Lu, Zhang, Liu, Li, & Deng, 2013). Lu et

al., further assert that by sharing and receiving advice from others in an online community, patients are better able to cope with their disease.

Other advantages to becoming a member of an online cancer support community include learning and understanding medical terminology which helps users with cancer understand what is being said to them when they meet with their healthcare professional. According to Harkin et al. (2015) patients who have just been diagnosed with cancer and visit their healthcare professional come away remembering very little of what has been explained to them and forget to ask important questions. This in turn leads them to turn to online communities to find someone who has experienced their particular cancer to find out what to expect and possible treatments. Graffigna, Libreri & Bosio (2012) suggest that patients who have access to online communities are able to become empowered and take charge of their own treatment and improve their mental well-being as well as help them make decisions about their treatment, based on advice from others suffering from the same condition (Graffigna, Libreri, & Bosio, 2012 p.324). Many users of online cancer communities are just "lurkers", meaning that they do not post but just watch and learn. Zhang et al., (2017) claim that of internet users as a whole, 90% lurk, 10% post and of those only 1% are "super users." They state that when using online cancer communities, there are super users who account for 1%, and these people post often and give advice to others, which enables them to build social capital (Cornwell, 2017). Zhang, Bantum, Owen, Bakken, & Elhada, (2016) maintain that the users who lurk have either a lesser form of cancer or have not had it for very long. Their research also suggests that lurkers do not get as much out of the forums as those who actively participate.

There are some disadvantages to using online cancer communities for information. Not all information is accurate, and users have to be able to sort out valid information from false. This can be very difficult, especially for cancer patients and their families who do not have medical experience. False or misleading information can lead to stress and depression. Often new users of these online communities become disenchanted and upset if they are unable to find the information they were seeking, especially if their particular form of cancer is not well covered or is very rare. Such users often leave

without gaining satisfaction. Even though family and friends are crucial as a support network, "peers who share similar problems can be a better choice when one needs emotional support such as empathy and encouragement from others" (Zhang, Bantum, Owen, Bakken, & Elhada, 2016). This supports Wellman & Gulia's (1999) theory that online communities can provide both weak and strong ties and that those people who have experienced the same or similar disease are better able to offer more specialised support.

Schweizer, Leimeister & Krcmar (2006) found through their research that cancer patients who had been using the internet for more than two years for cancer-related topics were more likely to develop virtual relationships (p. 4475). This has its drawbacks as users who develop close relationships can become very distressed when they discover that their friend has succumbed to cancer (Schweizer, Leimeister, & Krcmar, 2006). A close look at the Australian Cancer Council Online Community pages, shows many people who have asked and been given help and information, and who have reciprocated when they are obviously very ill themselves. In one particular instance, a man, who had undergone many operations and procedures in order to deal with his primary and secondary cancers, suddenly stopped commenting, despite always appearing to be there for others. In a later additional post, using her husband's user name, his wife explained to the rest of that particular group that her husband had died and that if they wanted to talk about their specific form of cancer they could contact her via her new user name, so even though her husband had succumbed to the disease she was willing to continue his legacy of helping others (Cancer Council, 2019).

As well as the foregoing disadvantages to using online cancer communities, there is also the problem that not everyone has access to these services. According to Statista, (2018) only 88% of Australians have access to the internet, whilst Harkin et al, (2015) state that these figures are similar in the EU, USA and Great Britain. Thomas et al., (2018) assert that whilst many families are connected and have access to the internet there are still a large proportion, approximately 2.6 million Australians, who include migrants, those with limited internet access and those with a low income are still unable to gain access to these valuable online resources (Thomas, Wilson, & Park,

2018).   Many of the unconnected people are in the 55 and over category. Thomas et al., state that of those who can access online communities, only one in five people in the 55+ age group access the internet for health advice, which they recognise is extremely low. Considering that many of these people are alone and isolated or in rural areas, this age group might also be concerned about sharing information online due to privacy issues. Brady, Seegers & Sanders (2016) claim that patients who use online forums to gather information about their condition generally are very careful about the amount and type of information they share with others in order to maintain their privacy. This view is supported by Frost, Vermeulen & Beekers (2014) who suggest that although online communities do offer benefits to patients, there are different levels of information that they are prepared to share. Clinical information about their condition and treatment being the type of information that is easily shared, others need this type of information if they are to offer advice, this type of information is seen as low risk from a privacy point of view. Whereas personal information relating to a person's home life or identity is the type of information which a patient would be wary of sharing in face-to-face situations with strangers so they would think twice before disclosing this in an online situation as it may compromise their anonymity.

From personal experience and research, plus research from others it appears that emotional and social support from others via an online cancer support community is as important to cancer patients and their family and friends as that which is gained from face-to-face meetings. The main advantages being that users can be anonymous, support can be gained from the comfort of their homes and not having to attend meetings, and they can take advantage of the knowledge of a large group of people who have or had cancer so are able to provide information and advice from a personal perspective. This positive experience can only be achieved by actively taking part, posting information and questions, and receiving information and support in return.

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