Experience and Sharing in Virtual Community Regarding Patients with Breast Cancer in Turkey: A Netnography Study

Mehpare Tokay Argan,
School of Applied Sciences,
Bilecik Seyh Edebali University, Turkey.
E-mail: mehparg.argan@bilecik.edu.tr

Metin Argan,
Faculty of Sport Sciences,
Anadolu University, Turkey.
E-mail: margan@anadolu.edu.tr

Abstract

The purpose of this study was to examine online support group to patients with breast cancer. The study applied a netnography to investigate and describe experiences, feeling expressions, and explanations from the perspectives of cancer patients in virtual groups. The results of this study revealed that four main themes (psychosocial benefits, experience, learning on disease and common interest about disease) that the patients can mainly indicate in the online groups and share their experience and feelings about cancer. The findings of research also indicate that interest in comments and evaluations made by people who have overcome cancer was the most important factor.

Key Words: Netnography, virtual communities, cancer, breast cancer, Turkey

JEL Classification: M 30, M 31, M 39
1. Introduction

Over recent years, psycho-social support has increasingly been considered significant in helping people to cope with cancer. This is particularly important in the light of the psychological morale for individual to cope with serious diseases. Cancer patients not only fight the serious disease, but they also try to cope with the psychology of cancer. One of the most important support points for cancer is any kind of psychological help from various groups or sources. Today, one of the most important sources of support for cancers is undoubtedly the internet, especially virtual health groups. Each day, the number of cancer-support forums in many countries is growing to provide psychological supports the people with serious or chronic diseases.

A significant idea about psycho-social support regarding internet sources is expected to result from these feeling, and experience sharing. The advantages of psycho-social support include relief, low-risk perception, positive examples, morale of healed cases. The support to the patient to cope with cancer is crucial, both for avoiding negative mood, and in terms of comfortable process of treatment. Beliefs about healing are critical when supporting comes from individuals having same disease or experienced people, based on achievement in the cancer treatment process.

Widely accepted and adopted beliefs in terms of patients can be very useful. A widely accepted patterns of psychological support can lead to advantages of immune system remaining strong or can prevent the negative mood from other healthy peoples. Positive signals or suggestions about the disease can directly affect patients with serious disease, either through direct recommendations or other supporting experiences, or through expressions about tackle of this problem. In addition, positive support includes success stories, examples of healing in the immediate vicinity, success stories on new treatment directions by individuals of virtual groups. The majority of the individuals having a story about cancer share positive views related to the treatment process. This paper represents an empirical study that employs netnography to learn role of virtual cancer group on experiences, feelings and beliefs, emotion sharing.

2. Literature Review

Today, virtual communities can provide a neutral, fairly low risk environment through which someone can express an opinion, learn more and develop relationships with others if they desire (Quinton & Harridge-March, 2010). Armstrong and Hagel (1996) classifies the online communities into four different categories: interest, relationship, transaction and practice. In health care marketing, there are many interest groups (Quinton & Harridge-March, 2010). Many of individuals in online interest groups come together in order to share feelings, information, experiences, advices on disease or health problem.
Online groups regarding consumption or marketing identify the main sources of information for marketing research (Kozinets, 2002). The consumer psychology literature likewise suggests that people come into the social marketplace to solve problems (O’Reilly et al., 2012). Similarly, in health context, patient also become a member of a virtual group to share health problems, to find a solution for the disease or to receive social support. In this regard, patient behavior is highly influenced by sharing, social support, social networks and online social context.

Langer and Beckman (2005) indicates that in many virtual communities people use internet message boards in order to exchange information and advice about product or services. Virtual community in health, reflected by interactive communication, is central to gain specific disease-related information and to share experiences among patients. Patient-centered information and experience sharing become one of the dominant features of today's online era. Especially with the increasing number blogs and community support communities and social media, patient-oriented virtual communities has increased. Therefore, one platform of support for patients experiencing socialization and exchange of information is online support groups or virtual communities (Tokay Argan, Argan & Ozer, 2016). Patients with common interests or disease gather virtually to share their health experience, ask questions, or provide emotional benefits and self-support (Eysenbach et al., 2004). A typical virtual community in health include a group of people (patients, doctors, professionals, members of general public) who have come together to share health information and personal experiences (Demiris, 2006). According to Eysenbach et al. (2004), virtual communities can be seen mental health and social support mediums (Tokay Argan, Argan & Ozer, 2016).

Virtual health communities represent a vulnerable population who need to connect via online social support groups (Davis & Calitz, 2014). According to Symister and Friend (2003), lack of belongingness may result in feelings of social isolation, loneliness, negative mood and hopelessness. Health-related virtual communities provide significant benefits to members, including cope with depression, decrease stress, share opinion and experiences (Loane & D’Alessandro, 2013). For this reason, virtual communities help chronically ill patients who want to maintain a positive mood and optimism (Davis & Calitz, 2014; Tokay Argan, Argan & Ozer, 2016).

3. Methodology

The concept of netnography was firstly defined by Kozinets (1997), in a study about fans of The X Files (O’Reilly et al., 2012). Kozinets defined netnography as “a written account of online cyber-culture, informed by the methods of cultural anthropology” (Kozinets, 1997, p.472). Netnography can be explained as the use of internet and virtual groups for the purpose of investigating or revealing concepts, themes, dimensions or factors underlying experiences,
feelings, cultures, and expressions regarding virtual groups, forums etc. Interactions or communication among consumers by online groups have been studied by using netnography (Kozinets, 2002), in order to reveal experiences, feelings, imagery, attitudes etc. (Langer & Beckman, 2005).

Netnography has similarities with ethnography, but it also carries a number of differences. Kozinets (2010, p. 5) underlines several features that distinguish it from ethnography. First, the interaction differs from the traditional ethnography. While ethnography is mostly based on one-to-one communication, however, netnography applies a variety of communications, e.g. text, sounds, images and other “virtual” expressions such as emoticons. Second, netnography uses more focused, quality and rich data, whereas ethnography relies on field notes and creating textual accounts (Lugosi, Janta & Watson, 2012). Conversational acts are analyzed rather than unit analysis as person. However in ethnography, the unit subjected to analysis is the person (Kozinets, 2002; Andreassen and Streukens, 2009; Sigala, 2012). This the main difference between traditional (ethnography) and online or virtual. The results of netnographic study’s sample do not represent other population. In other words, findings of netnographic study are interpreted in terms of a particular sample (Kozinets, 2002; Sigala, 2012).

Netnographic studies are especially useful for exploring experiences and feelings in virtual groups. Basically, netnography focuses mainly on two data collection methods (Kozinets, 2002; Belz and Baumbach, 2010; Sigala, 2012). The first one is that the data directly copies from online communication in the virtual community. The second one underlines that the researcher collects the data regarding his/her observations of the community and its members, interactions and meanings (Sigala, 2012).

Kozinets (2002) underlines that if the online forums or virtual communities met five criteria, they are considered suitable for use in ethnographic studies: matching research questions; having high pasting traffic, having different messages, providing rich data, having a high degree of between-members interactions (Sigala, 2012). Kozinets (2010, p. 89) outlines six criteria for selecting online site, arguing that they should be: “(1) relevant to the research focus and questions; (2) active, with recent and regular communications; (3) interactive, having flows of communication between participants; (4) substantial, in terms of numbers of users; (5) heterogeneous, involving different participants; and (6) data-rich” (cited in Lugosi, Janta & Watson, 2012, p. 841). In this study, a netnography of main virtual forums and communities was carried out in order to respond to the research questions regarding cancer patients. More clearly, the netnographic study, focusing on the cancer patients’ experiences of information about their illness, was carried out from a virtual group as internet source. In order to reveal experiences, feelings and sharing, interactions of virtual cancer group regarding patients with breast cancer, netnography methodology was applied. In other words, this study applies
netnography to investigate the dimensions of experiences, feelings of cancer patients as reported on virtual group.

Sample selection must be made precisely, for this reason purposive sampling is often used in such researches. From this perspective, a virtual cancer community or group was chosen for the research purpose and in terms of its ability of representing. We selected forums, virtual communities or blogs according to the following criteria: relevant information about breast cancer, large amount of activity by members, interactivity with the audience and substantiality of the information (Kozinets, 2010, p. 89). Virtual groups of cancer patients were suitable for implementation of this netnographic study because: they are specifically designed for enabling cancer patients to post and discuss their disease; and they have a large number of active members that are highly engaged in online experiences and cancer related information uploads. Interaction among members in this virtual health group is very high. Interaction is also natural in terms of very special disease. Netnographic data were collected via gathering expressions, opinions and experiences of the virtual group comprising individual with cancer or having experience with their relatives. Virtual groups’ observation and contents were the main tool in collecting data. Virtual or online groups are a source of information that “can contain rich, detailed, longitudinal data about individuals and their consumption practices, values, meanings and beliefs” (Kozinets, 2007, p. 138; Kulmala, Mesiranta & Tuominen, 2013, p. 24).

4. Results and Conclusions

The study aimed to examine the experiences, relationships and interactions among members of online cancer group. This netnography study outlines the relationships and experiences among virtual community members. Data were gathered from the online cancer groups and forums and netnography was used for analyzing them. Overall, four major themes were identified: psychosocial benefits, experience, learning on disease and common interest about disease. The findings of this netnography study reveal that online cancer patients’ interactions and experiences enable patients to share feeling about disease and understand the nature of cancer. Thus, knowledge and experience about disease and the sharing of recovered samples and feelings have a positive influence on individuals of cancer based online group.

The findings of the study highlight that patients with chronic or serious diseases use virtual groups or forums in order to exchange information, share experiences, and feelings. It seems that the combination of information about cancer treatment and psycho-social support provided by experienced members not only provides useful information but also online-life interaction. These findings indicate that these sharing or interactions may emotionally contribute to treatment process of cancer patients.

Important findings were generated by the netnographic analysis on virtual group of breast cancers. The most important finding in this study was that virtual community concerning with
cancer is used as means to obtain information related to the disease. This finding is in line with the suggestion that virtual communities are common knowledge-sharing tools (Chen, Chang & Liu, 2012; Tokay Argan, Argan & Ozer, 2016). As indicated by Loane & D’Alessandro (2013), dynamic interchangeable health information and socio-psychological support are main determinants of virtual community for patients with cancer. The information can also often related to sustaining care and a better quality of life of the disease. Additionally, it should be noted that willingness to provide spiritual strength is one of the most important benefits of this kind of virtual communities (Tokay Argan, Argan & Ozer, 2016, p.39).

5. Limitations and Future Research

This netnographic study has several limitations. As with all qualitative research, interpretation the results is limited by only one specific virtual community. This research highlights the role of virtual disease group in terms of providing useful health information and experiences among group members. However, based on the exploratory and preliminary nature of this research, future validation of the findings is needed. Further, multi online group based netnography research assessing relationship, experiences and interactions is also required.

References


