

# Functions of Social Networks in a Community of Cancer Patients: The Case of Instagram

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**Abstract** Cancer patients are faced with numerous issues, such as physical and psychological symptoms, cognitive dysfunction, and impairment in social participation and carrying out personal tasks. Nowadays, the positive effect of psychological interventions on improving chronic diseases has been verified. This paper studies the ways that cancer patients use social networks using qualitative content analysis. Evaluating 6 Instagram pages via qualitative content analysis, we reached 3 classifications. These classes included: (1) Information gathering which had 3 subclasses including desire to gain information on cancer, Health information and information on cancer prevention, (2) Sharing experience which manifested in 4 forms: behavior toward others at the time of diagnosis, stress during treatment, empathy and course of disease, and (3) Support, which includes 3 subclasses of emotional support, financial support and social support. Our results showed that potentials such as interactivity and availability has turned social networking into a convenient tool for cancer patients; they can use these sites to fill their emotional void, gain information and benefit from the shared experiences by others.

**Keywords** Cancer, Social Networks, Patients, E-health

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## 1. Introduction

Incurable diseases cause a lot of pain and suffering, which can potentially bring patients closer to death. These patients constantly experience anger, depression and despair during the courses of treatment and recovery. Since cancer is a life-threatening disease, being diagnosed with it makes the patients panic, Sadness, sorrow, tension and anxiety [1-3], are normal reactions to crises that an individual may face during cancer treatment and almost all cancer patients experience these feelings. Despite medical advances, developments in cancer treatment and the increased number of cancer survivors, still the deep sense of fear and helplessness that this disease creates is unparalleled [4]. Diagnosis and treatment of cancer can also affect directly or indirectly a patient's physical and psychological quality of

life [2, 4, 5].

Patients who consider their disease more dangerous, chronic and uncontrollable become more passive and incompetent, causing them to have weaker social functioning and more psychological problems. Therefore, we cannot limit the cancer treatment to the clinical aspects. Nowadays, the positive effect of psychological interventions on improvement of chronic disease has been verified [6, 7]. Psychologists, relaxation therapists, spiritual guides, specialist nurses and other mental health professionals play an important role in a patient's confrontation with feelings, worries and concerns; moreover, there are factors involved which could enable the patients to see their current condition of pain and suffering with a broader outlook. Researchers believe that hope helps the body to fight cancer [8, 9]. In a research in 2007 about hope in advanced diseases, Mun Hong showed that support from family and friends, religion, acceptance, self-awareness and knowledge on the current conditions are important factors for increasing hope and fighting chances [10]. Compared to usual care, the internet, as a source, presents potentially better answers to the patients'

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needs for independency, experience and communication. Anonymity and accessibility from home at all times has made internet more supportive in terms of independency and breaking geographical, time and financial boundaries. Having ample information and support tools (such as consultation, treatment planning, and behavior change support) can provide a wide range of proper support and also enable the patients to control their situation better.

As an interactive tool for accepting or changing health behavior, social networks can provide emotional and social support for the public. Informed patients might ask better questions and be able to manage their disease more effectively; they could even supervise and intervene in order to improve their treatment. Internet Chat groups can help the patients fight their disease and act as an alternative; in addition to common networks, online social support could change the course of various diseases [11]. Also, sensitive medical and health issues which are taboo due to cultural restrictions can be discussed through social networks [12].

Media function in the area of health has been proven in many studies [4, 13-16]. According to Toma (2013), using the social media such as Facebook can play a fundamental role in improving the self-esteem of different users [17]. Just as the media can put people under severe psychological pressure, it also has the ability to relieve their stress and bring about peace.

Blumer (1969) showed that in order to actually understand an individual's experiences, we need to pay attention to the interpretation of objects, situations or actions of others. Therefore, we have to distinguish between the biological visualization of the disease and its social definition. Even if no social interaction occurs in a similar manner and the person himself/herself changes from one situation to another, there is still the possibility of discovering similar processes which transpire during an incurable disease such as cancer. Analyzing the patient's account of the disease helps to reach an accurate understanding of its social effects, especially in the case of incurable diseases [18]. Now considering the known functions of social networks and their interactive nature, we might be able to use them in order to satisfy the needs of cancer patients; this of course requires analysis of patient accounts and their interactions through these networks. Thus, in this research, we seek to identify the Instagram functions as a social network for cancer patients.

## 2. Methods

Data collection methods such as interviews and questionnaires that restrain the subjects cannot make a true evaluation of an individual's experiences and feelings; therefore, in the past few years researchers have been using the ethnographic method to understand people's feelings and the depth of their behavior.

In the late 1990s, with the introduction of Netnography by Kozinets as a method for analyzing online communities, researchers started adapting and expanding their

ethnographic methods widely based on the reflective accounts people posted online; researchers recognize this method as a "modern qualitative research method consistent with ethnographic research techniques that studies emerging cultures and societies through computer-mediated communications" [19]. Netnography follows 6 steps, some of which overlap:

- 1 – Research design
- 2 – Entrée
- 3 – Data collection
- 4 – Interpretation
- 5 – Ensuring ethical standards
- 6 – Research presentation

In addition to the descriptive-analytic method for understanding the subject, this study also uses netnography to discover the dimensions of social networking in order to help cancer patients. Netnography is widely used in online research; however, there have not been many studies in Iran using this particular method in this field. Therefore, such an effort would result in a new set of standards for research in this domain.

To enter the research field, we searched for suitable pages using the Instagram application and hash tags (#), such as cancer, cancer patients and cancer communities or associations, which eventually led to selection of six pages as sources for data collection.

The second stage involved data collection. In this study, we collected data by directly copying people's comments and related news from active communities in Instagram. Characteristics such as being related or complete were considered when selecting data, especially for members' comments and experiences.

The selection process is presented in Table 1.

**Table 1.** Names of the selected pages and number of items for the purposes of interpretation

	Website name	Item	Number
1	Cancercharity.ir	Post	64
		Comments	76
2	breast.cancer.campaign	Post	175
		Comments	8736
3	Manizhe.cancer	Post	145
		Comments	5342
4	Cancelcancer_ir	Post	188
		Comments	2376
5	Cancer.campaign	Post	97
		Comments	354
6	Piroozibarsaran	Post	132
		Comments	547

In the present research, gathering and analysis of data were done simultaneously, through continuous comparison of the data; all in all, 6 Instagram pages were analyzed, a process which continued until saturation.

In order to achieve our research objectives, i.e. to

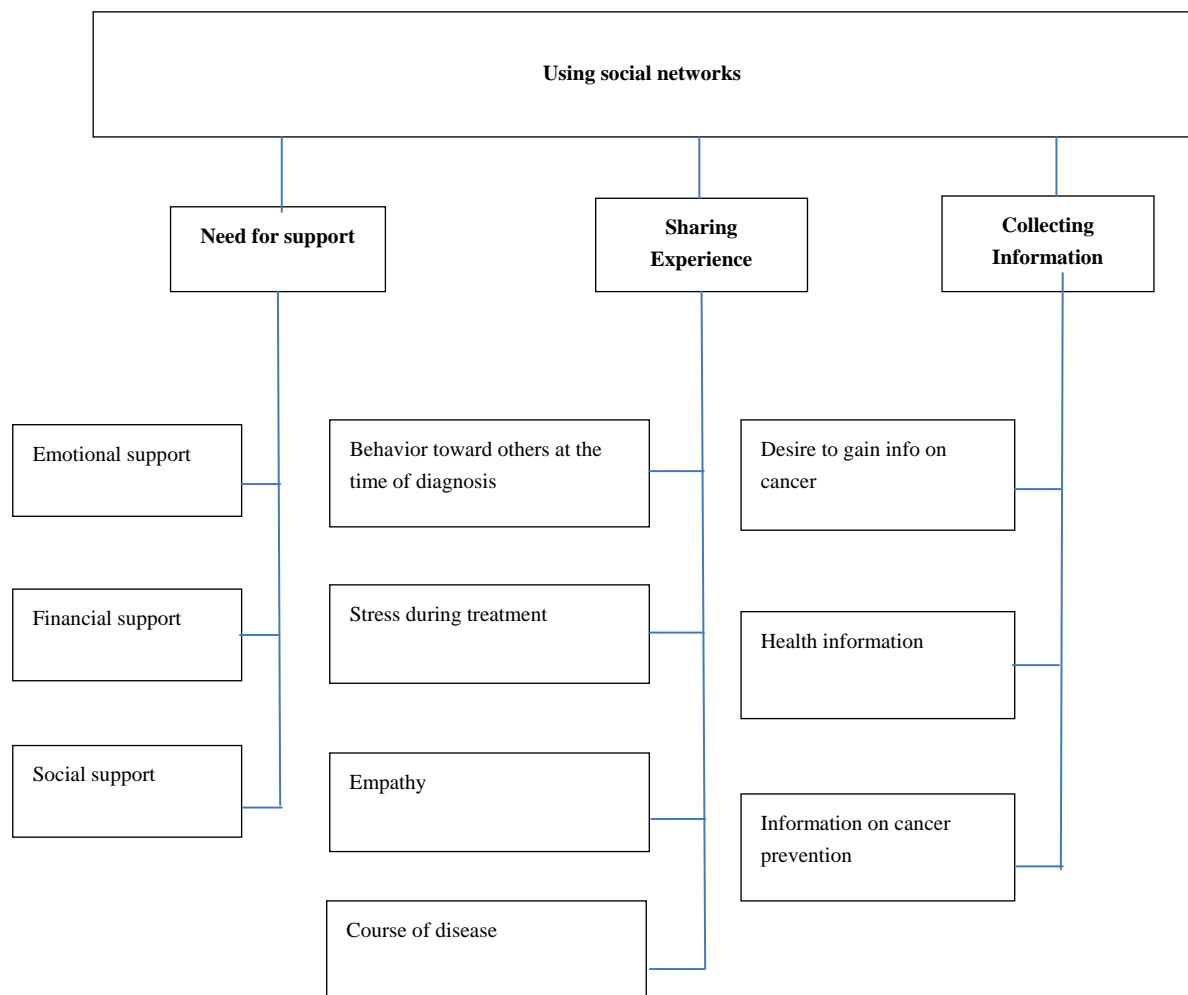
understand the dimensions of social networks in helping cancer patients, data collection and analysis was done in 6 steps: 1- Becoming familiar with the data, 2- Producing initial data coding, 3- Searching for themes by reviewing different types of coding extracted from the previous step, 4- Revising the themes and comparing them with the data again to insure their reliability, 5- Defining and naming themes, and finally 6- Preparing the final report.

We also used a few methods to insure validity and reliability of the data, including revision by observers; in this regard, we sent parts of the statements transcript along with the related coding and emerged classes to few observers, so that they could evaluate our analysis and comments on the validity of items. In order to calculate the reliability, we used encoding (inter-rater) agreement. In this method, codes which were assigned similarly by two coders were identified as “agreement” and those which differed were marked as “disagreement”. In this study, encoding reliability was calculated at 69% via the formula; since this value was

higher than 60%, it verified the reliability of the coding method.

### 3. Results

Data collection lasted 2 months; after determining the basic concepts, 680 initial codings were extracted from our data collection. After reviewing them for a few times, these codings were summarized and then classified based on similarities and congruence; then, after more in depth review and comparison of the classes, their inner meanings were identified as the primary themes. The primary themes were named conceptually and abstractly based on their nature. At the end, all the codings were classified in 3 classes and 10 subclasses using the inductive approach. Consequently, these themes show the nature of how cancer patients use social networks. Figure 1 summarizes these findings



**Figure 1.** Themes obtained from research results

1 – Collecting Information: one of the most significant contexts emerged in this study was patients' need to gain information when faced with diagnosis and on the other hand, their family's need to gain information on cancer prevention. In this regard, it seems that social networks can be a great tool for implementing educational and informational programs in the field of health; this need for information is reflected in the 3 following concepts:

1, 1 – Desire to gain information on cancer: one of the main reasons patients turn to pages in social networks such as Instagram is to search for a source of information which quickly answers questions people have when faced with diagnosis or suspicions of having the disease. In this regard, one follower commented: *"does marital status affect breast cysts?"* or *"how long after chemotherapy will the hair loss begins?"*

1, 2 – Health information: information on doctors in the city of residence or nearby accessible cities is an informational need frequently seen in comments. It seems that people like to hear about trustworthy doctors and treatments from people who are directly involved with cancer. For instance, one user commented: *"one of my relatives had breast cancer, and unfortunately it has now reached her lungs; I wanted see if it's curable or not, how much time she has, and if you know of any good oncologists in Tehran specializing in lung cancer, she is in a very bad mental state, please help"*.

1, 3 – Information on cancer prevention: Considering the increased rate of cancer in Iran, a lot of people are worried about being inflicted with it; by reviewing the comments, it was evident that aside from people who themselves or their close relatives were fighting with cancer, some people were merely interested in those pages to prevent the disease or find methods to diagnose it at an early stage. Regarding the concerns of a user, one of the pages responded that: *"ladies who worry about breast cancer should lose weight, exercise, and get an ultrasound every few months or so; you should also need to note that not all breast lumps are signs of cancer. I had a lump myself, which after medical examination and lab tests turned out to be just a little cyst caused by the thyroid hormones"*.

2 – Sharing experience: Creating an Instagram page allows the patients to share their experiences on disease progression, symptoms and general health conditions. Through interaction with others experiencing a similar situation, patients can have a better and more informed understanding of their health conditions. They can draw a real picture of what happens in life through the disease based on others' experiences. They can also get a clearer picture of the disease progression timeline and know which symptoms predict worsening of the disease. Experience sharing manifests in 4 forms:

2, 1 – Behavior toward others at the time of diagnosis: in Iran, the main focus is usually on the physical aspects of cancer, whereas we need to consider cancer treatment and the psychological aspects of disease as two separate topics. We observed that most patients were afraid of revealing their

disease to their friends and family members, and they were interested in knowing other people's experiences when confronted with this issue. One user stated: *"Hi, I have a question, it was right around my college exams when I became aware of my disease, everything fell apart instantly, I haven't gone back to school for the past 2 terms; you wrote in your memoirs that you went to college, I want to ask how? When I receive medication and I either faint or sleep all the time, how can I go back to school?"*

2, 2 – Stress during treatment: Fear of possible death, stress of confronting family members, stress caused by the fact that life's going to undergo significant changes, dysfunctional life, difficult and irritating treatments, physical deformities caused by the side-effects of surgery and adjuvant therapy, and the constant uncertainty caused by the threat of recurrence are among patient concerns identified in this paper; many users showed interest in expression of mutual experiences. In this regard, one of the users wrote: *"my mom finished chemo and radiation therapy this summer, but she's been coughing for about a month now. I'm worried her disease has relapsed again"*.

2, 3 – Empathy: Empathy has better effects on disease acceptance than sympathy. Patients initially seek practical support and then they seek for empathy because sympathy and pity diminish the sense of personal responsibility and make the patient dependent and annoyed. A user wrote in this regard: *"Honey I totally understand how you feel, I had the same disease in 2011 and it recurred in 2015, but know this, if you put your will to it, you can put the disease to shame; be strong; if you're determined and hopeful, you'll end up even better than before, because you'll enter a world of spirituality which will calm you and give you peace; I look forward to the day that I see your posts as lively and cheerful as mine today"*.

2, 4 – Course of disease: Using patient experiences during the course of disease was favored by many of the users; there were a lot of questions regarding personal issues, stages of treatment and personal experiences on dealing with stages of disease more conveniently. *"When will the hair start growing back?"* and *"Doctor Kaviani told us to eat as many walnuts as possible"* were among the comments related to this issue.

3 – Need for support: One of the issues frequently repeated in comments, by most patients and also people seeking information on cancer, was the need for emotional and social support from close family members and financial support from related institutions. A lot of users stated that through interaction with others, their disease and problems became easier to tolerate, and it prevented depression and isolation. This need for support manifests in 3 forms:

3,1 – Emotional support: Nowadays, alongside medical fields like oncology, surgery and internal medicine, psychology and psychiatry play an important role in improving cancer patients' quality of life. Emotional support prevents isolation and loneliness and brings about a sense of peace. One of the users wrote: *"Even though I was feeling sad and gloomy, I visited your page and your post really*

*made me calm. As always you are role models to me.” Or “my aunt starts chemotherapy next week; pray for her. I showed her your page and her mood improved; it’s a blessing that you’re here”.*

3, 2 – Financial support: Aside from psychological aspects, financial burden of special diseases is usually a heavy burden on families. Most patients require more information on the matter. Additionally, most people don’t know where to seek for help; it seems that social networks are able to bring financial institutions and philanthropists that support cancer patients in need of help closer together. In this regard, we can mention the following comment: *“if you know anyone who has cancer and is in need of financial assistance with medical expenses, please introduce them to me along with their medical documents and receipts of purchase”.*

3, 3 – Social support: In the past few years, scientists recognized a positive relationship between social support and health. Social support is known as one of the most popular and distinctive methods of dealing with loneliness and despair. The need for connection and involvement in social interactions is essential for emotional and physical health and welfare. There is evidence of social support that have supportive effects on cancer patients [20, 21]. Many of the patients felt satisfied with these pages; one user expressed: *“I’m so happy you are healthy, I’ve been reading your posts since the first day of being diagnosed and your statements always filled me up with energy”.*

## 4. Discussion

This study aimed to determine how cancer patients use social networks. The findings showed that the users in cancer related Instagram pages hugely consist of patients and their families. Three dimensions were identified in this study as the functions of social networking for cancer patients. The first dimension was information gathering; it seems that one of the main reasons why users visit these pages was the need to gain information at the critical moments of being diagnosed, or even before that, from people whose relatives have cancer. 3 subclasses emerged in the information gathering class, including desire to gain information on cancer, health information and information on cancer prevention. The importance of information gathering for cancer patients has been verified by other studies as well. Graffigna et al., did a qualitative research on the knowledge exchanged between cancer patients and the suitability of online communications for these exchanges. They too reached the conclusion that internet-based communication between patients and caregivers is quite valuable; through the internet, patients and their caregivers can have a close relationship which would involve the individual in the treatment process [22]. Also, Aitken et al. (2014) showed that in the United States, in the case of special diseases, most of the attention drawn to social networks was related to health, treatment and follow ups, changing health behavior and lifestyle, and details related to health insurance; they also

revealed that 70% of Canadians use the internet for gathering health-related information, and 92% of them use the Google search engine instead of health portals [23]. Muhamad et al., did a research in 2011 on 400 breast cancer survivors who used the internet; their findings showed that 22.5% of the survivors used the internet to gain information on breast health issues; they were interested in using the internet to gather information on cancer and treatment options, especially radiation therapy, chemotherapy, health management, treatment side-effects and suitable diets. That research also revealed a significant relationship between internet usage and five independent variables including age, education, annual income, place of residence and nationality/ethnic group [24].

Sharing experience is another function of social networks that users emphasize on. Online chatrooms allow the patients to share their experiences on disease progression, symptoms and overall health conditions. Through interaction with others experiencing a similar situation, patients can make a more informed decision and have a better understanding of their health conditions. They can draw a real picture of what happens in life through the disease based on others’ experiences. They can also get a clearer picture of the disease progression timeline and know which symptoms predict worsening of the condition. Sharing experience manifests in 4 forms: behavior towards others at the time of diagnosis, stress during treatment, empathy and course of the disease. In this regard, other studies have verified the sharing experience through cyberspace. One of these studies was done by Seale et al., in 2006; through a new method, they did a comparative keyword analysis to compare the men and women with cancer; for this purpose, they conducted 97 interviews in two internet-based cancer support groups. The patients considered internet forums as a rich source of experiences on disease and gender differences and stated that a significant difference in gender functioning was evident. They found that men with prostate cancer mostly use the internet to search for information, whereas women with breast cancer mostly seek emotional and social support; and although forums are in fact very public and visible environments, it seems that they are used by both genders as relatively private settings for the exchange of personal and intimate experiences [13]. Hoybye et al., did a study in 2005 on online interaction and effects of narrative in an internet breast cancer support group. In this qualitative research, using ethnographic case-study method they explored how internet support groups can break the isolation that follows cancer and chronic pain. Through analyzing the storytelling emerging on the Scandinavian Breast Cancer Mailing list and using participant observation and face-to-face or online interviews, they investigated the motivations of 15 women who chose internet to counteract social isolation after breast cancer. The results showed that the women were empowered by the exchanges of knowledge and experience within the support group. Internet was considered a means for finding ways of living with breast cancer. Their study suggested that internet support groups have an important

potential for the rehabilitation of cancer patients [25].

The last function of social networking identified in this study was support, which consisted of 3 subclasses of emotional, financial and social support. According to researchers, support is vital for psychological well-being of cancer patients. When a person is diagnosed with cancer, the need for support increases; this need can be satisfied through family, friends, nurses, doctors and other people [26]. As the starting point of a causative process, the mechanism through which social networks and social support might have positive effects on psychological, physical and social health moves toward health outcomes.

Through satisfying the basic needs of man for companionship, intimacy, sense of belonging and confidence in self-worth, social networks and social support can improve health and welfare no matter how high the stress level is. Also, social networks and support can make an individual more capable to access information and identify and solve problems. If support can help to reduce uncertainty and produce the expected results, it will consequently increase a sense of personal control in special situations and different areas of life. Therefore, people's interactions through social networks might help them reinterpret events or have a more positive and productive attitude toward problems [14]. Several studies were done on the effects of support on cancer, including: Peters-Golden did a study on social support for cancer patients in 1982; they expressed that social support has been identified as an important factor in cancer. However, it's been witnessed that patients sometimes avoid joining face-to-face support groups due to reasons such as the stigma associated with cancer and the reluctant behavior of others. Examining the perceived social support in 100 breast cancer patients and anticipated social support among 100 disease-free individuals, Peters-Golden reached the conclusion that healthy people direct stigma and reluctant behavior towards cancer patients, and that is one of the causes behind social isolation of these patients [27]. Therefore, online cancer support groups have become quite popular, because they might not have some of the issues of traditional groups such as the inconvenient pressure of meetings and worries about babysitting, and on the other hand, they have characteristics such as convenient 24-h access from home, anonymity, access to personal and professional support information and mutual experience. Online support groups have special benefits for users who might not be able or interested in going to face-to-face meetings, and they can help cancer patients maintain their social relations [28]. Also, the amount of social support available to an individual can be an important mediator for diminishing the consequences of disease; there is evidence which suggests social support can both have a protective and coping function in illness and health [29]. In a study by Sugawara in 2012 on 51 active cancer patients on Twitter found that most of the communication in this network was related to treatment and other kinds of psychological support. At the end, they reached the conclusion that at present there is a rapidly

evolving network of cancer patients engaged in information exchange via Twitter; this network is valuable in sharing of psychological support among cancer communities [30]. Beaudoin et al., did a research in 2007 on the benefits of online social support for cancer patients; they stated that their research revealed two strong relationships: (1) between social media and social capital; and (2) between social capital and public health. They merged these two relationships and presented their model consisting of the following four steps: Internet usage --- social capital --- social support --- health outcomes in terms of stress, depression and coping. Their findings suggested that the internet can be a positive cyber venue for cancer patients as they confront illness, undergo treatment and seek out support [31]. Also, in a research on social support for cancer patients, Helgeson et al., showed through descriptive studies that emotional support is most desired by patients, and in their correlative studies they suggested that emotional support has the strongest associations with better adjustment to the disease [32].

In this article, we searched for cancer activity in the Instagram by use of hash tags (#), such as cancer, cancer patients and cancer communities or associations, which eventually led to selection of six pages as sources for data collection. Our limitation in this research was that the only 6 active pages in community of Iranian cancer patients in Instagram found. Based on the results, it is hoped that the necessary infrastructure will be provided to facilitate this kind of communication.

## 5. Conclusions

In this paper, using qualitative content analysis, we studied the functions of social networks for cancer patients. Evaluating six Instagram pages via content analysis, we reached 3 classes. (1) Information gathering with the 3 subclasses of desire to gain information on cancer, health information, and information on cancer prevention; (2) Sharing experience which manifested in 4 forms: behavior toward others at the time of diagnosis, stress during treatment, empathy and course of the disease; and (3) Support, which consisted of 3 subclasses: emotional support, financial support and social support. Based on our results, we can say that because of potentials such as information and experience sharing and protective functions, social networks are convenient tools to fill the voids that cannot easily be filled through face-to-face interaction.

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