What Do Relatives of Turkish Women with Ovarian Cancer Share on Websites? : A Qualitative Research

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Summary

Purpose: To purpose of this study was to examine the interpretations shared by patient relatives on websites. *Materials and Methods*: A descriptive qualitative approach was used. We used an online search engine, Google, and performed a search utilizing the terms 'ovarian cancer, 'sharing', 'experience' between 2009-2019 to determine the sample, and 78 shares were included. Data were analyzed using content analysis. *Results*: Qualitative analysis revealed four themes: (1) cancer perception, (2) reactions during the disease period, (3) difficulties during the diagnosis and treatment period, and (4) coping strategies. It was determined that caregivers of women with ovarian cancer had a negative perception of the disease, had more emotional reactions, had unmet needs, and examined alternative/complementary medicine practices. *Conclusions*: This study provided information about the experiences of relatives of women with ovarian cancer during the diagnosis and treatment process.

Key words: Ovarian cancer; Caregiver; Website.

Introduction

Ovarian cancer is the 8^{th} most frequent cancer type in women in the world [1] and the 6^{th} in Turkey [2]. Thanks to the developments in the treatment of ovarian cancer and increasing survival rates, changes are experienced in patient care outside the hospital, which increases the physical, emotional and social responsibilities of patients' relatives. The women who receive ovarian cancer diagnosis and their relatives experience difficulties during diagnosis and treatment [3]. It is possible that caregivers of women with gynaecologic cancer face the effects of the disease and treatment on their relationship, role, treatment monitoring, symptom management, personal care and emotional and financial support [4, 5].

In the case of cancer diagnosis, most patients and their families usually do an internet research prior to consulting their doctors [6, 7]. In previous studies, patients mentioned that search for information and support on the Internet about treatment and doctor preference according to the cancer type [8, 9]. In another study, caregivers stated that used the Internet to have information and support for caregiving, and very few joined blogs or online discussion forms of caregivers [10]. Patients and their relatives frequently refer to blogs as they cannot share their feelings and thoughts with the healthcare staff. Nurses spend the longest time with patients and their relatives. For this reason, nurses, who are healthcare staff, have important roles in the protection from ovarian cancer and in the physical and psychosocial compliance of the patients and their caregivers. Evaluating the positive and negative emotional experiences of the individuals and their relatives in this process with qualitative methods will provide important data in planning nursing care. The aim of the study was to examine the interpretations shared by patient relatives on websites.

Materials and Methods

Design and sample

The data for the study is determined by researchers and collected via one of the frequent search engine. This study was carried out as a review design by using Google between 2009-2019. The relatives of women with ovarian cancer who shared interpretation on internet forums were included in the study.

Data collection

The search results on the Google search engine between January 2009 and December 2019 have been reviewed with key words in Turkish [over kanseri <ovarian cancer>, yumurtalık kanseri <ovarian cancer>, paylaşım <sharing>, deneyim <experience>]. This study contains the searches made between 03.04.2019-14.04.2019. Our results include the last decade due to increasing use of technology and the popularity of internet forums in our country in recent years.

Reviewed language is Turkish and country is selected as Turkey, so as to reach all results are made only with specified keywords in the search engine from Turkey. When the unrelated pages started to repeat, internet browsing was terminated and the pages not related to the topic were not included in the review. Forums with open access were ex-

©2020 Güler et al. Published by IMR Press. amined and the sharing of relatives of women with ovarian cancer were selected. Users share their experiences and questions in the forums with their nickname. As a result of this review, 88 sharing were detected. The sharing was read from the recent one towards the oldest one; and after the expressions of the patients and the repeated sharing were excluded, a total of 78 sharing with different nicknames were got.

The selection flow of sharing is given in Figure 1.

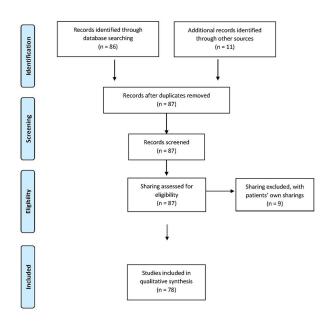


Figure 1. — Sharing flow diagram.

In these internet forums, there were headings related to feeling, opinions and experiences that were parallel to our purpose. At the same time, selected forums were most frequently used. Besides in this discussion boards, women can post a message or comment related to the topic at hand. On this platform, women could create new headings or could write under available headings. Forums are open to the entire population. Turkey Statistical Institute, the 2019 household information technology (IT), according to research use; internet usage was 75.3% in individuals aged 16-74 in 2019. According to the results of household information technology use survey, 88.3% of the households had access to the internet from home. Everyone can use these forums freely.

Data analysis

The pages accessed through the determined keywords were placed in the tables prepared according to the criteria determined by the researchers.

Ethical considerations

Research ethics board approval (Approval No. 2019/12-10 on 08.05.2019) from university. Because internet forums are online and openly accessible and shared comments are open to the public, there was no need for informed consent.

Results

It was determined that the relatives of the patients who had sharing were mostly the child, mother, sibling, spouse, nephew and friend of the patient. As a result of the searches on the blogs, four themes, seven sub-themes and twentyfive topics were determined (Table 1).

Theme 1: Cancer perception

Facing ovarian cancer

Ovarian cancer was expressed with the words 'death' and 'secret killer' by the patient relatives. In addition, they also said that they perceived cancer as a chronic disease and tried to live with it.

"It was Stage 3c... Unfortunately; this disease cannot be known before this stage. That's why they kill it as secret killer."

"Unfortunately, this is a difficult disease, you must think about it as a chronic disease that always exists in your life".

Theme 2: Reactions during the disease period Emotional reactions

The relatives said that during the disease period they experienced emotional reactions like anger, power /weakness, helplessness, despair, disappointment, fear, anxiety, denial, uncertainty, hiding the disease, sadness.

"For example, I was very angry. I was more impatient and intolerant towards my children. I was mad at them subconsciously for not being able to walk away if something happened to A. But it is not their fault that their mother is going to die"!

"I have read many texts about this disease, but I have never seen anything nice. The worst part is that no one can do anything".

"My mother is an angel, she is a very good person, why don't bad people die, and this happens to my angel mother".

When the sharing of the relatives in blogs was examined, it was determined that had fears for many reasons like the severe treatment period, relapse, and genetic transmission of ovarian cancer.

"I know that genetic factors are involved in cancer. My fiancée is 32 years old now, and she carries the risk of cancer genetically. Are there tests to determine whether she carries the risk or not?"

"She responded quite well to the 6^{th} chemotherapy, but I've heard that the disease returns after the treatment is ended. This is my only fear".

Theme 3: Difficulties in diagnosis and treatment period

Late and incorrect diagnosis and treatment

The patients' relatives said that they initially applied to different units like urology and internal medicine unit because of the symptoms that were not specific to the disease, and they were diagnosed late because of the loss of time and were treated incorrectly.

Table 1. — The themes and sub-themes on the sharing of the caregivers of the ovarian cancer patients.

THEME	SUB-THEME	TOPICS
Cancer perception	Facing ovarian cancer	Secret killer
		Death
		Chronic disease
Reactions during the disease period	Emotional reactions	Anger
		Helplessness
		Disappointment
		Anxiety
		Uncertainty
		Sadness
		Power/Weakness
		Despair
		Fear
		Denial
		Hiding the disease
Difficulties during the diagnosis and	Late, incorrect diagnosis and treatment	Lack of specific symptoms
treatment period		Applying to different medical units
		Need for information
	Unmet needs	Difficulty in contacting the doctor
		Economic problems
		Insufficient communication
Coping strategies	Support systems	Professional help
	11 5	Visiting those who defeat the disease and other patients
	Cultural and individual coping systems	Religious beliefs and applications
	1 8 7	Intrinsic motivation
		Search for alternative and complementary treatment

"My mother had swollen stomach, her groin ached, she did not go to WC, and gasped. Firstly, we went to the urology unit. They said she had cysts on the ultrasound. She was referred to the general surgeon... there was increased fluid in the pelvis... She was then referred to the gynecologist".

"My mother had stage 3c ovarian cancer, the doctor did not understand. They said she had kidney stones; and 1.5 years was lost for us".

"We traveled for 4.5 months to get a diagnosis; we went to the gastrology, urology, gynecology, all departments in the hospital".

"My aunt had ovarian cancer. However, my aunt's disease could not be diagnosed and stomach treatment was applied due to her complaints. So cancer progressed".

Unmet needs

It was determined in the blogs that patients' relatives felt angry with the healthcare employees because of their inappropriate communication styles, they could not receive information about the disease period, and had difficulty in contacting the doctors. As a result of this, it was determined that the patients' relatives searched information about the progression, prognosis, examination results and treatments of the disease on the Internet. In addition, it was also determined that they had problems like delayed treatment or lack of access to treatment because of economic difficulties.

"Doctors consider people as machines. Saying that the patient dies or lives... it is an ordinary sentence for them. They always say the worst of all, because if they say something good and the patient gets worse, they will be held responsible. No one would object if the patient became bad, therefore, doctors would not make you feel gloomy".

"What is the reason of this disease; who has it more; what are its symptoms; what must be done for early diagnosis? What should be the tested before the operation? Because of the workload in the state hospitals, it is not possible to meet your doctor who is in continuous operation faceto-face within this short time. For this reason, we need to interpret the results on our own according to the reference values".

"We went to the state hospital because we had no adequate financial means. We went to the hospital many times for 3-4 years. They prescribed the same painkillers and antibiotics and sent us back. When we went to a private hospital, they immediately decided for a surgery".

Theme 4: Coping strategies

Support Systems

It was determined that the patients' relatives received professional therapy support; and wanted to meet other patients who had beaten the disease. "In America, cancer is considered as a disease affecting the whole family. When A was diagnosed, the hospital appointed a therapist for us. The children, me and A went to therapy for two years. It was incredibly helpful. You experience many things and you need support, it is hard to handle it on your own".

"We collapsed as a family in terms of demoralization, I just want to meet people who beaten this disease; and want to introduce my sister in terms of demoralization".

Cultural coping systems

The patients' relatives said that in the disease period, they tried to cope with the disease with prayers, which are one of religious beliefs and practices.

"Healing is in our God, friends, let us pray willingly and sincerely. May Allah heal all patients and protect everyone from the cancer".

Individual coping methods

Most of the participant said that they used intrinsic motivation methods like motivating themselves and their patients by trying to be strong to cope with this disease.

"However, the important thing is to give moral motivation to your patients, to keep yourself strong and standing. You may be facing the most difficult days of your life; however, do not make it felt by your patients. When my mother saw that we were happy and not anxious, she began to consider life positively and had a great improvement. Makes your patients feel that you need them".

It was also determined that the patients' relatives asked each other questions and looked for alternative and complementary medicine applications on the Internet.

"... I believe that herbs distribute healing, but which plants should be used for this disease, please, anyone share it exactly if there are anyone knowing or trying".

"Does anyone know which foods are good for ovarian cancer"?

"Doctor, somebody talked about a vaccination in Istanbul. We do not know the details. Perhaps you have information about this. Is there such a vaccination for this disease?"

Discussion

In this study, it has been determined that patients' relatives expressed ovarian cancer as secret killer and their reactions to the disease was negative. In addition, it has been determined that patients' relatives had difficulties such as late diagnosis and unmet care needs and use cultural and support systems in coping.

Theme 1: Cancer perception

In this study, participants described the disease as the "secret killer". Ovarian cancer is defined as the "silent killer" because it presents at an advanced stage and does not have a specific screening program [11, 12]. The adoption of the metaphors like "silent killer" and "sneaky disease" reflects the fact that the disease reaches an advanced stage

before it is diagnosed; and is almost always deadly [13]. This may be because the symptoms of ovarian cancer are not specific to it, and there may be the lack of knowledge of relatives as the reason. Meanwhile, the patients' relatives also described ovarian cancer as a "chronic disease". The survival durations of the patients who are diagnosed with ovarian cancer increases with developing treatment methods [14], which may require follow-up of the survivors of the disease and lifestyle changes. The patients' relatives might have likened ovarian cancer to chronic diseases in terms of these aspects. The perception of the disease as a chronic disease may cause that the patients move away from the idea of death. In this way, it might affect the communication and compliance of the patients' relatives with healthcare professionals in the diagnosis and treatment period in a positive way.

Theme 2: Reactions during the disease period

The diagnosis and treatment period of ovarian cancer is a very difficult process. The patients' relatives experience complex and intense feelings in this process. Anger is one of the feelings faced by the patient relatives. They stated that they felt angry with the doctors because of the misdiagnosis and inappropriate communication during the diagnosis process. Although family members are important in care of the patient, they are not involved in the treatment process sufficiently by healthcare professionals [15]. Ferrel et al. stated that the caregivers felt angry and shame with the doctor because of the diagnosis at advanced stage [16]. Healthcare professionals should be aware that patients' relatives can experience emotions such as anger, embarrassment, and sadness and the patients' relatives who cannot control their anger might damage the diagnosis and treatment process of the patient. For this reason, healthcare professionals should be supportive to the relatives of the patient to develop their positive coping skills and can use support groups in clinical settings to enable patients' relatives to express their feelings and thoughts.

In this study, we determined that the patients' relatives experienced fear due to relapse, side effects of the treatment, and genetic transmission. In previous studies, it was shown that caregivers were afraid that they might also be affected by the spread of cancer [11, 17, 18] and that they or other family members might have ovarian cancer [16]. Health care professionals should provide counseling for the caregivers about ovarian cancer which diagnosis, treatment, its being non-contagious, and inherited genetic. In addition, the relatives should be directed to specialist professionals from whom they can receive counseling about inherited genetic.

When participants learned of the diagnosis, they stated that they experienced denial, sadness, and weakness. Stiolos *et al.* determined that when patients' relatives faced firstly the diagnosis they experienced shock, denial, disappointment and emotional destruction [18]. In another study that examined unmet needs, it was determined that the caregivers had difficulties in managing their emotions about prognosis [17]. In this study the reactions of the patients' relatives during the diagnosis process are similar to the loss responses. Healthcare professionals should be aware of their emotional reactions in the diagnosis and treatment process of patients' relatives and should try to tolerate and absorb the reactions of their relatives.

Patients and their relatives tend not to speak to hide that they are worried about each other. In our study, the patients' relatives said that they hid the diagnosis from their patients, and experienced uncertainty about the prognosis. Studies show that caregivers are concerned about the psychological well-being of their patients [11], and also that they avoided discussing the disease with their patients [19]. The patients' relatives might face uncertainty because of the patient' health, possibility of relapse, prognosis and future plans [17, 21]. It was determined that the patients' relatives faced many negative emotions. However, it is understood that the patients' relatives tend to hide these feelings to protect their patients from being sad, disappointment and fear, which might increase the emotional burden of the patients' relatives. Health care providers should evaluate and support emotional burdens of patients' relatives. When care of the patients is planned, they should determine the information levels of the patients and their relatives, and avoid giving different and double messages.

Theme 3: Difficulties faced during diagnosis and treatment period

In the present study, many of the patients' relatives stated that when symptoms of the disease were detected, they referred to many different units, doctors did many examination procedures during the diagnosis process, and they could not provide correct guidance, they could not reach the doctor when they needed him/her, and the process of diagnosis and initiation of treatment were delayed. The patients' relatives stated that the wrong treatments were given to their patients for these reasons. Ovarian cancer is the most deadly-progressing cancer type among gynecological cancers with its symptoms emerging at advanced stages [12]. In addition to these, the first symptoms of the disease are the symptoms like abdominal distension and indigestion, which are not specific to this disease [21, 22]. In addition, there may be personal reasons like delayed diagnosis of ovarian cancer, not having knowledge on the symptoms, lack of access to healthcare, or inadequate access to it; or there may be some reasons related to healthcare staff like lack of detailed history, lack of sufficient time allocated for the patient, and matching the symptoms with non-serious diseases [23]. In this study, too, one of the most important problems that were stated by the patients was the disruptions and delays in the diagnosis and treatment period, which is in line with the literature. Therefore, healthcare professionals should contribute to correct diagnosis as early as possible by providing adequate time for the patients and their relatives. It is considered that the navigator nurse, who will work on oncology, will contribute to the solution of the problem by establishing communication among the special-

ists. The caregivers of ovarian cancer patients state that they need information about the disease, treatment, and future conditions [18]. It is understood that there is a need for providing information on the diagnosis and treatment process for the caregiver. It is also understood in this respect that an important way that is used for this purpose is the Internet. When the Internet is used correctly, it is a very useful, fast and easy way to access information. However, there is a lot of information on the Internet, which might be incorrect and harmful for patients and their relatives. There may be non-scientific treatment suggestions on the Internet, which may delay the diagnosis and treatment of patients and may affect their treatment in a negative way. For this reason, healthcare team should establish positive communications, and investigate the information sources and their quality for patients and their relatives.

Pozzar et al. (2018) examined the perspectives of patients, caregivers and physicians on ovarian cancer treatment decision making. While physicians described experiences with patients who preferred to pursue complementary and alternative therapies in lieu of recommended treatment, caregivers stated that playing a supportive role in the provider selection process. Caregivers attributed the treatment decision to the physician. Here, a sense of urgency to start treatment played a role in the caregiver's willingness to follow the physician's advice. In this study, it is similar to our results. Our findings indicate that relatives made recommendations and asked for recommendations regarding the doctor and the hospital. One of the important things in the diagnosis and treatment process is the communication of healthcare staff. In the same study, it was reported that the relatives paid attention to interpersonal communication of the physicians when they chose the physician [24]. The patients' relatives who were not satisfied with their physicians were referred to another physician. Informing the caregivers about diagnosis and symptoms of the disease, and including them during treatment process might be effective in avoiding communication accidents with healthcare providers. The trust relation that is established with the healthcare provider contributes to the increase of psychological well-being by meeting the needs of the caregivers.

One of the problems faced during treatment process is the economic problems. The relatives stated that their patients could not benefit from healthcare service at an adequate level because of economic problems. Participants were forced to change working hours, leave work, retire or cover the cost of the treatment [17, 19, 25]. While patients considered receiving chemotherapy or radiation at a facility closer to home, physicians also acknowledged the importance of social service agencies in arranging transportation for patients with limited financial resources [24]. Economic problems are the highest burdens in caregiving process. Since economic problems influence caregiver burden, healthcare providers might provide support and referral to financial and medication assistance resources.

Theme 4: Coping strategies

When statements of the participants were examined, it was determined that they wanted to receive support from individuals who had survived cancer before. The caregivers of the cancer patients used the Internet to search for support for their patients [10]. One of the most common problems of the caregivers about social support systems was that they were not aware of these systems. Hand *et al.* found that caregivers expressed their social support needs as calling a support group, contacting other caregivers, and receiving professional support [3].

Social support is defined as one of the greatest unmet needs of caregivers, and it is frequently emphasized that they feel isolated. It was determined that caregivers who received social support did not feel alone, they reorganized their family processes, and helped to increase their wellbeing [16, 17]. It was reported that the depression and anxiety rates increased in caregivers who had low social support [19]. The patients' relatives feel inadequate in supporting their patients in transition to diagnosis, in progression of the disease, and in the end of life. The inadequate information, support and guidance that are provided by healthcare professionals makes caregivers feel inadequate [18]. The interactive internet-based communication system is an opportunity for caregivers in providing social support and skills training. Additionally, social media was brought to the agenda as supporting communities, which might match the caregivers [3]. For this reason, organizing a national forum will prevent relatives and patients from being misinformed and will contribute positively to the treatment process. Also, it helps to reduce the sense of inadequacy by reducing the caregiver burden.

In the present study of ours, it was determined that the patients' relatives employed the prayer method in coping with the disease. It was reported that spirituality is an important source of coping underlying the positive meaning and purpose of the disease while maintaining hope despite poor prognosis [16, 18, 26]. This study have similar result with the literature. The fact that the healthcare team is smiling towards the relatives of the patients, sharing the beliefs of relatives, participating in activities that will develop their beliefs, and supporting them to express their thoughts and expressions will contribute to the development of their coping skills.

It was also determined that the patients' relatives shared about alternative treatment methods to cope with cancer. The caregivers for patients with ovarian cancer looked for alternative/complementary therapies [16]. The use of technology is an important field in decreasing the caregiver burden in the healthcare model. Caregivers frequently use the Internet to learn information and support for cancer patient [3, 10]. For this reason, healthcare providers can decrease the caregiver burden by informing the relatives about alternative and complementary applications.

There are strong and limited sides of searching with Google. It is a strong tool since it is free, easily accessible.

However, sharing of patients' relatives who do not have internet access or who do not know how use the internet could not be included in the sample. We guess that internet users are more often female and younger and have higher levels of education. Another limitations are the presence of forums requesting permission for access and closed groups on social media. The descriptive characteristics of the relatives who made sharing in the forums and the cancer stages of their patients were unknown. Therefore, the results are very general. This study includes 78 sharing. Whether there are duplicates in the sharing has not been determined due to nicknames. Because the same people may have shared using different nicknames.

Despite these limitations, this study of patients' relatives with ovarian cancer in Turkey is the first study that examined the sharing on the Internet. Therefore, our results provide important information to understanding experiences and unmet needs of relatives of women with ovarian cancer. Our findings indicate that relatives as well as patients need support systems and information during disease and treatment process. We suggest that in-depth interviews should be conducted through face-to-face interview method in order to understand experiences and needs of the relatives of women with ovarian cancer in future researches. Although in many countries there are national support forums created by health care professionals to share knowledge and experiences of the relatives, there is not any national forum in Turkey. Creating a national forum will prevent relatives and patients from being misinformed and will contribute positively to the treatment process. Although it was not an expression of patients' relatives, this study is thought that it included sharing related to patients with epithelial ovarian cancer due to clinical symptoms. Because symptoms and age groups of sex stromal and germ cell ovarian cancer are different, it is thought that our study did not represent these groups. This is limitation of our study.

For those who want to access information about treatment and care in ovarian cancer via the internet, it is necessary to increase the quality of existing sites or to prepare more qualified, up-to-date, reliable and easily accessible sites by experts in the field.

Meeting needs of relatives will reduce their levels of anxiety and stress and prevent them from experiencing a sense of burnout. Thus, it will enable relatives to actively participate in patient care and prevent possible complications.

Conclusions

Ovarian cancer is a complex process for patients and their relatives because of delayed diagnosis and poor prognosis. When the patients' relatives learn of the diagnosis, they give reactions that are similar to loss. They feel ignorant because of the nature of ovarian cancer, and search information. The lack of specific symptoms of the disease causes late diagnosis, and receiving treatment only in developed hospitals. In this case, the relatives may face economic difficulties and need social support systems and use social media and prayers as effective coping methods in this process. It is very important that healthcare professional, who care for patients diagnosed with ovarian cancer, become aware of these problems faced by their relatives. Nurses should not forget to take care of the patients' relatives as well when they provide care to the patient from the first encounter till the last moment. In this way, the needs of the patient, and the diagnosis and treatment of the disease may be planned in a more accurate way.

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Conflict of Interest

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