



How Parents of Children with Cancer Seek Information Through Online Communities: A Netnography Study

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ABSTRACT

Aim: This study aims to examine how parents of children with cancer seek information through online communities, using netnography methods from qualitative study types.

Materials and Methods: The study was carried out through two online communities where parents of children with cancer in Turkey communicate with each other. The data were obtained from the parents' posts to online community platforms covering the period between September 2nd and November 2nd, 2017. The data were collected using the netnography method and analyzed within the principles of this method.

Results: A total of 580 written posts (information sharing) were sent within the interval in which the study was conducted, and 208 of them, which were posted by 131 parents, were analyzed and coded. Accordingly, three themes were defined in terms of codes as follows: "disease," "treatment and side effects", and "non-treatment" posts. The themes of "disease" and "treatment and side effects" included questions in which the parents were seeking information, whereas the theme of "non-treatment" mostly included posts in which the parents were seeking emotional support from other parents in the communities.

Conclusion: The way in which parents of children with cancer seek information through online communities is mostly related to their questions and posts parallel to the cancer process. In this process, the parents were found to seek emotional support.

Keywords: Children with cancer, parent, the internet, information seeking, netnography

Introduction

Pediatric cancers are increasing daily across the world (1). Pediatric cancer, which may occur in all ages of childhood, is a chronic disease requiring high-risk decisions depending on diagnosis and treatment (2). Therefore, it causes physical, psychological, social, and economic changes in the lives of both children and parents (1-5). Although parents receive supportive information and information about treatment from health professionals, they also seek more

information from other sources about the cancer process (6). In today's modern world, the Internet has become a new information source for parents of children with cancer. Online communities also provide parents of children with cancer with an opportunity to create and use online social networks in order to gain information and support from people with similar experiences (7).

Health-focused online communities are defined as online platforms in which patients and families, who suffer

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from the same or similar diseases, share health information and experiences with each other and also provide social and emotional support to each other (7,8). There are many such platforms for parents of children with cancer. After their children are diagnosed with cancer, parents seek information and support (because of fear, anxiety, and not knowing what to do) (9). Many recent studies have drawn attention to parental online information-seeking behaviors and practices (2,6,9-18). Pehora et al. (10) report that Canadian parents actively use the internet to obtain child health information. DeLuca et al. (11) emphasize that parents of newborns mostly use the internet in search of newborn health information. Knapp et al. (12) point out that parents of children with life-threatening diseases use the internet substantially to find relevant medical information. Han and Belcher (9) report that parents of children with cancer use the internet to find cancer-related information, share experiences, and seek support. Gage and Panagakis (2) state that after children are diagnosed with cancer, parents start to use the internet mostly to get psychosocial support, rather than using it as a source of information about the disease. However, the number of studies on online information-seeking approaches adopted by parents of children with cancer is still very limited (2,9). This is the first netnography study conducted in Turkey to examine the information-seeking practices of parents of children with cancer via online communities. Using netnography methods, this study aimed to examine how parents of children with cancer seek information through online communities.

Materials and Methods

Netnography is defined as a new qualitative research methodology that adapts ethnographic research techniques to study cultures and communities that emerge through computer-mediated communication (19-21). Netnography is less intrusive and cheaper than other research methods (19,20). It follows certain methodological stages and directions: determining the research purpose, determining the appropriate online community, data collection, ensuring compliance with ethical standards, analysis and interpretation, and presentation of the research (19,22) (Figure 1). All the detailed features of the netnography method are described in a study by Kozinets (19). Ege University Health Sciences Scientific Research and

Publication Board; 270-2017. Permissions of the moderators were obtained before the shares of the two network groups in this study were evaluated within the scope of the research.

Study Sample and Data Collection

First, an online community screening was performed using the Facebook search function and the keywords "cancer," "cancer and child," and "mother father" on the Internet. The Hope Foundation for Children with Cancer (KAÇUV), which has the highest number of foundation members in Turkey about 56.795 users (<https://www.facebook.com/Kacuv/>) was identified as the first online community for the study. Later, an online community of 30.055 users, called "dance with cancer" (<https://www.facebook.com/groups/kanserledans/>) was identified as the second online community for the study.

People can become members of the online communities KAÇUV and Dance with Cancer after their online membership requests are approved by the website moderators. These online communities have been established to support patients with cancer, and the rules to be followed by the members are monitored by the moderators. Dance with Cancer produces relevant content for all members from all age groups diagnosed with cancer. Members can send posts using their personal member accounts. Both online communities are specifically established for cancer patients and do not include medical advice.

Permission to collect data for our study using the online community platforms was obtained from the online community moderators. Dahan and Levi (23) emphasize that researchers should remain only as observers in netnography studies to collect robust data. Therefore, in the present study, the researchers only joined the online communities as members, and then collected the data objectively.

The shared content in this data included members' information-seeking and support-seeking approaches regarding cancer (questions, answers, and experiences). A total of 580 posts were sent in the study period between September 2 and November 2, 2017. Of these, 208 (about cancer, child, parent, or treatment) were included in the study. These posts were posted by 131 member parents who used the words "my child," "my son," or "my daughter." Posts sent by parents of children with cancer were included in this study, and those sent by adult cancer patients were excluded from the study.

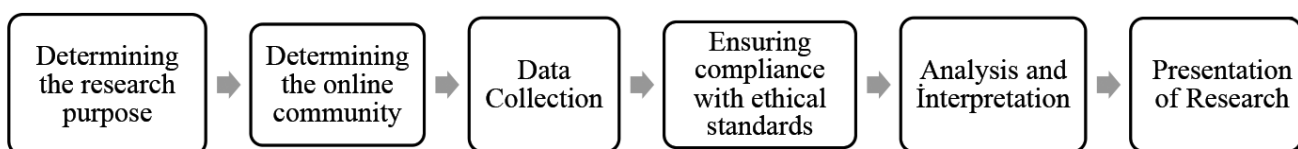


Figure 1. The methodological process of netnography
Kozinets R.V. *The field behind the screen: Using netnography for marketing research in online communities.* *J. Marketing Res.* (2002) 39:61-72.

The members were observed to use mostly colloquial speech and sincere expressions in their posts. However, there were many spelling and punctuation errors in their statements. The examples given in this study are presented without correcting the punctuation and spelling mistakes.

Statistical Analysis

The research analysis was carried out in accordance with the principles of coding and analysis adapted from the netnography method of Kozinets (19). The data were evaluated by two researchers. After reading all posts in the sample more than once, the researchers identified three main themes: (1) "disease" posts, (2) "treatment and side-effects" posts, and (3) "non-treatment" posts. Based on these themes, descriptive encodings of the posts were made until a new theme did not occur. After the codes were discussed and finalized by two researchers, they were transferred to the MAXQDA Analytic Pro 12 (release 12.3.1) program for analysis.

Results

The research results are discussed under two headings: "gender distribution" and "themes."

Gender Distribution

Parents emphasized their parental identities, using the expressions "my son," "my daughter" and "my child." Parents included 16 fathers and 92 mothers. However, 23 of the parents defined themselves only using the word "parent's" and did not specify their identities as mother or father (Table I). This study uses the word "parents" referring to all mothers and fathers whose posts were included in the study.

Themes

Three important themes were determined regarding the parents' information-seeking through online communities: "disease," "treatment and side effects" and "non-treatment" posts. The distribution of themes is shown in Figure 2 (MAXQDA Analytic Pro 12).

Parents of children with cancer (n=131)	n	%
Mother	92	70
Father	16	12
Unspecified parent*	23	18

*These are parents who did not state whether they were mothers or fathers

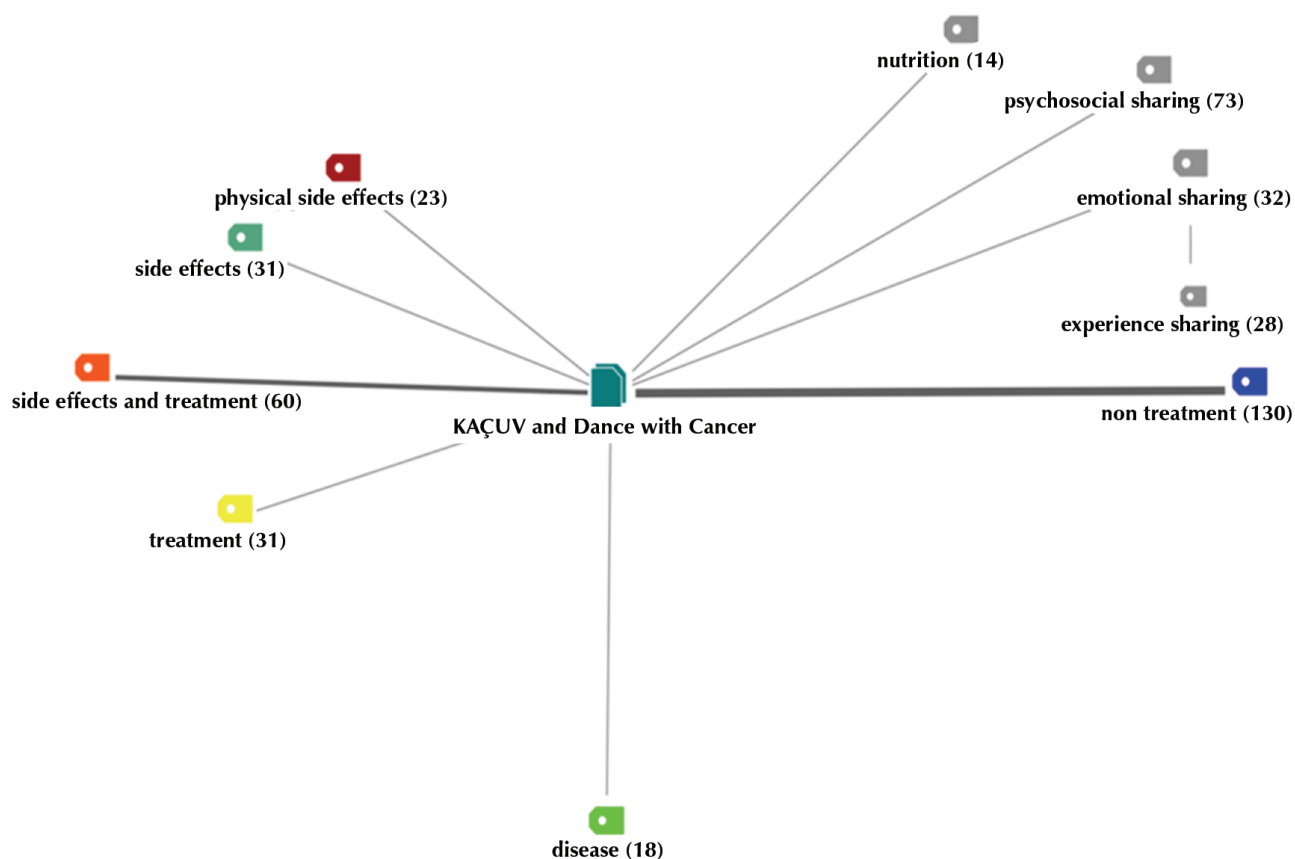


Figure 2. Distribution of the most posted sub-codes

1. Disease Posts

The parents asked questions that reflected their information-seeking about the disease (n=18). Some of the posts in this theme are listed below:

"... what kind of a path is hepatoblastoma disease following?," "...we are currently waiting for the nerves to heal, magnetic resonance results are clean, will the treatment continue?," "what is the percentage of relapse in acute lymphoblastic leukemia after the transplant?" and "what is the rate of secondary cancer?."

2. Posts about Treatment and Side Effects

The "treatment and side effects" posts were high in number (n=60). The parents had clear questions:

- "We are in the first month of my son's leukemia treatment, what will happen?" and "My child frequently receives radiation therapy and magnetic resonance, how long will this continue?"

One of the parents directed his/her information-seeking questions about treatment to other parents, and he/she was found to get answers containing emotional support statements:

- "Is there anyone who has undergone autologous tissue transplantation due to leukemia, if so, could you please write to me?" "Get well soon! My daughter underwent

marrow transplant surgery when she was 4 years old, it was one year ago, Thank God! We are OK now" "my daughter underwent the surgery on 24th of October the last year, we used femodal pills, she received radiotherapy for 30 days and had 8 chemotherapy sessions. Anaplastic ependymoma grade 3. She is 4-5 years old now, the cancer was in her brain stem. I hope my little baby survives."

The "physical side effects of chemotherapy/radiotherapy" posts (n=23) were interesting. The most commonly mentioned side effects were fever, mucositis, nausea, loss of power, malaise, hair loss, and gait. In addition, there were information-seeking posts regarding side effects such as cough, organ damage, muscle laziness, growth retardation, pain, and numbness in the hands (Figure 3, MAXQDA Analytic Pro 12):

- "What is the cause of fatigue after radiotherapy?," "The hearing loss has started, so what should we do?," "my child doesn't want to eat, saying (he/she has) nausea, what method should I follow?," "... the nausea does not disappear despite the drugs," "... how should I talk to my child? how should I tell my child to eat?," "... how to get rid of the pain of mouth sores caused by chemotherapy?," "My child is recovering from the medication that he receives for mouth sores, but after a short time these sores reappear, and my child is having trouble even in drinking water. What should

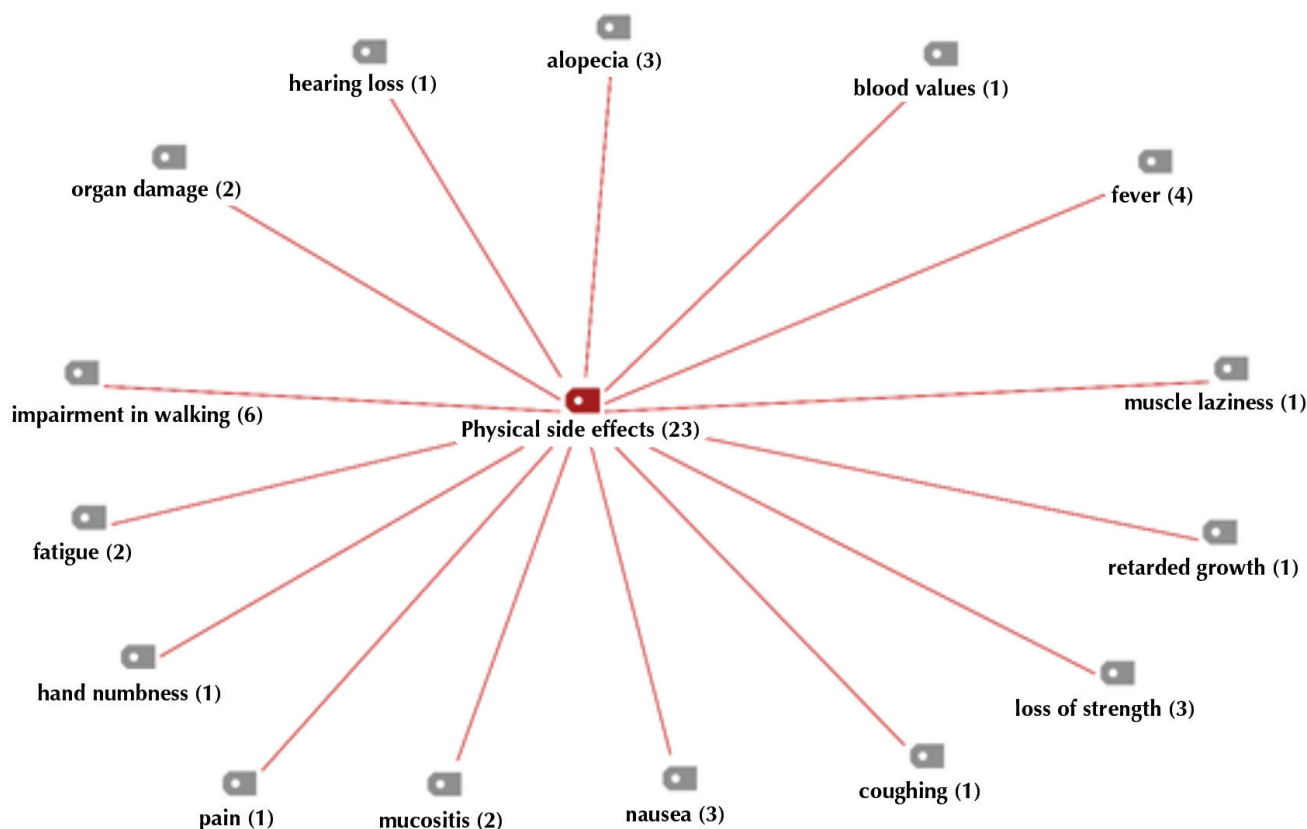


Figure 3. Distributions of the sub-codes regarding physical side effects of chemotherapy/radiotherapy

I do?" "My child doesn't want to eat, saying his stomach is sick, how should I proceed?" "The nausea still continues despite the drugs we used."

One of the parents sought information in her post, but also referred to the traumatic feeling that the side effect posed for her child: "The children do not cry because of the disease, but they are very upset because of their hair loss" and "Finally she could fasten hair-clips to her hair, and now she has ponytails."

3. Non-treatment Posts

The non-treatment themes made up the most heavily used area (n=130), and included posts about psychosocial conditions (n=73), emotional expressions (n=32), experience-sharing (n=28), and nutrition (n=14).

"Non-treatment" posts constituted the most emotionally intense category, as these posts included discussions about parent experiences, treatment results, parental expectations, and parents' support-seeking expressions. Some remarkable posts with supportive and promising emotional expressions were as follows.

- "My child struggled with the same disease, now (she is) 3.5 years old, we're good now, we have recovered from the disease," "Your greatest medication is morale and motivation... Never think badly," "I hope you get good news when your treatment is over," "Thank God! We're all good, we will overcome it (the disease) ..."

One of the parents explained that these supportive expressions had a positive impact on her:

- "My dear friends, I have read through my old posts, I was moved to tears. Sometimes, I asked some questions for my daughter suffering from neuroblastoma, sometimes I asked for prayers, sometimes I shared that the chemotherapy wasn't working, and you gave me support, I shared with you that my daughter's imaging was clear and you were happy for me, this was so precious to me, most of the time I was able to stand strong with the support of my friends."

Apart from the questions about treatment and its side effects, parents asked remarkable questions about nutrition for their children and searched for information: "what can we eat?" "Are cola or chips forbidden?" "Is it enough to keep the vegetables in vinegar for 20 minutes?"

Discussion

This study was conducted to examine how parents of children with cancer seek information through online communities. In addition, it is the first netnography study conducted in Turkey to examine information-seeking practices of parents of children with cancer via online communities. The majority of those who sent posts were mothers with caregiver roles. Gage and Panagakis (2) and Han and Belcher (9) conducted a study of parents of children with cancer and reported that it was mostly mothers who

cared for their children, so mothers posted a higher number of posts to the internet than fathers did. Plantin and Daneback (18) examined the information-seeking practices of parents of children who were patients and observed that mothers constituted the majority of parents actively using the internet. In general, mothers take an active caregiver role for their children with cancer, because cancer is a chronic disease, the treatment is challenging, and it has side effects reducing the quality of life.

The cancer treatments that begin immediately after diagnosis of the disease include surgery, chemotherapy, radiotherapy, biotherapy, and stem cell transplantation (1,3). Parents communicate with many healthcare professionals during and after this complex cancer treatment. In addition, parents become decision makers in the treatment process by undertaking the primary caregiver role for their children with cancer (24). Therefore, they are responsible for closely monitoring the health and treatment of their children (24,25).

In our study, parents were in search of information about cancer, its treatment, and side effects. In addition, they were observed to look for non-treatment-related support. These results were consistent with parents' information-seeking and support-seeking behaviors observed in similar studies (2,6,9-18).

In addition to their own information-seeking about the "disease" and its "treatment and side effects," the parents were observed to seek information about what other parents with similar health problems do and know. Yeh et al. (26) report that parents make a lot of effort to obtain information about their child's disease and exchange information with other parents to manage the disease's progress and side effects. In fact, treatment-related side effects of pediatric cancers are difficult to assess and take a long time to manage (3,5). Henström et al. (27) emphasize that cancer treatment is a very traumatic process. Similarly, in our study, the parents also emphasized the traumatic aspect of cancer treatment. In a study conducted by Hildenbrand et al. (28), one of the parents involved in the study had stated, referring to her child, that the most difficult part for her was the treatment process. From the posts, parents were observed to undertake the primary care of their children in the treatment process and in the accompanying side effects, to follow the treatment methods and procedure, and to seek relevant information. Wainstein et al. (6) and Tuffrey and Finlay (16) report that the majority of parents use the internet to search for more information about the disease and treatment. DeLuca et al. (11) point out that parents share the questions of "what?" "What happens," "How will it be treated?" and "Is it treatable?" while seeking information about the disease. As can be seen, the parents' information-seeking practices and

behaviors in this study are similar to those observed in the literature. Gage and Panagakis (2) emphasize that the internet is a secondary information source in the online information-seeking practices used by parents of children with cancer. They also report that parents of children with cancer send posts regarding the basic information about cancer and its treatment, using such questions as “What is transplantation?” and “How is it done?” which are similar to the questions posted by the parents in our study.

Children with cancer are always at risk of dying (1,4). The parents exhibited their information-seeking practices by sending posts about how they felt about this possibility and how to deal with it. In cancer, the treatment process not only affects the quality of life of those children with cancer and their parents (29), but also leads to anxiety and depression in the parents (26,30,31). Therefore, in the present study, the parents also wanted to have information about the disease and sought emotional support.

In the “non-treatment” posts, the parents were observed to seek emotional support. The parents used supportive and promising emotional expressions in the posts they sent to other parents whose children had suffered from the same health problems. Studies indicate that parents need emotional support during the treatment process and get support from other parents’ posts, including statements of hope, prayer and good wishes (2,9). In our study, by sending posts like “Thank God! We are well now, we will recover” and “I hope we will get good news”, the parents also expected other parents to send them posts including statements of hope-prayer-good wishes. In a study conducted by Han and Belcher (9), one of the parents of a child with cancer said that “some people in the community were very inspiring. I felt I was growing spiritually and emotionally, just by reading their writings”, which indicates that the parents seek both information and support from online communities and share their feelings and emotional states through these communities. Similarly, in our study, parents were observed not only to seek information about the disease of their children, but also to seek emotional support from other parents in similar situations. This emotional support positively affects them. Studies show that sharing supportive expressions and experiences on the internet positively affects the quality of life of parents of children with cancer (2,9).

The parents’ information-seeking behaviors indicate that they have parental potential with a tendency to wonder, want to learn, and share. Parents clearly and sincerely expressed their feelings, sorrows, and expectations, as well as their need for informational and emotional support regarding the difficulties they experienced with regards to their children.

In this study, another point outside the themes was noticed when the parents’ posts in the two online

communities were examined: there was no information provided by an oncologist or pediatric oncologist. This is a highly significant situation, because health professionals (oncologists, pediatric oncology nurses, etc.) can provide accurate and safe information. Pehora et al. (10) pointed out the need for health professionals to play a role in improving accurate and reliable information access on the internet. Another study emphasized that oncologists and pediatric oncology nurses can provide parents of children with cancer with reliable information on the internet (9). It will be meaningful to include this issue in new studies.

Study Limitations

Netnography, a qualitative research type, was used in this study. The posts of parents in only two online communities were included in the study, which is an important study limitation. Another study limitation is that the data were collected over a very limited period of time. These qualitative data were descriptive and exploratory; they were not designed for formal hypothesis testing. In addition, although internet use is widespread nowadays, the possibility of existing parents who cannot reach the Internet constitutes another study limitation.

Conclusion

Parents of children with cancer seek information through online communities, mostly searching for information about cancer, its treatment, and side effects. In addition, parents also seek emotional support from parents in similar situations in these online communities. The parents provide emotional support to each other. There was no information from an oncologist or from a pediatric oncology nurse among the posts sent through the online community platforms in our study. Therefore, online pediatric oncology specialists and pediatric oncology nurses and health professionals should be made aware of online communities so they can provide reliable information and professional support in these areas.

Ethics

Ethics Committee Approval: Ege University Health Sciences Scientific Research and Publication Board; 270-2017.

Informed Consent: Permissions of the moderators were obtained before the shares of the two network groups in this study were evaluated within the scope of the research. Personal privacy and parental nicknames were not shared.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Concept: C.S.G., S.Ş., Design: S.Ş., C.S.G., Data Collection or Processing: C.S.G., Analysis or Interpretation: C.S.G., S.Ş., Literature Search: C.S.G., S.Ş., Writing: S.Ş., C.S.G.

Conflict of Interest: No conflict of interest was declared by the authors.

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References

1. Marcadante KJ, Kliegman RM. *Oncology, Nelson essentials of pediatrics E-Book*. 7th ed. Elsevier Health Sciences, 2014. p. 534-42.
2. Gage EA, Panagakis C. The devil you know: parents seeking information online for paediatric cancer. *Sociol Health Illn* 2012;34:444-58.
3. American cancer society web site (homepage on the internet). New York: Cancer in children, 2017 (cited 2018 may) Available from: <https://www.cancer.org/>
4. Wood ME, Phillips GK. *Hematology/Oncology secrets*. Elsevier Health Sciences, 2003. p. 381-93.
5. Kudubes AA, Bektas M. Effect of fatigue on quality of life in pediatric oncology patients. *J Pediatr Res* 2017;4:96-102.
6. Wainstein BK, Sterlin-Levis K, Baker SA, Taitz J, Brydon M. Use of the internet by parents of paediatric patients. *J Paediatr Child Health* 2006;42:528-32.
7. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *J Gen Intern Med* 2011;26:287-92.
8. Argan TM, Argan M, Özer AA. Netnographic study on virtual community of patients with spinal cord injury (SCI) in Turkey. *Journal of Internet Applications & Management* 2016:31-43.
9. Han HR, Belcher AE. Computer-mediated support group use among parents of children with cancer-an exploratory study. *Comput Nurs* 2001;19:27-33.
10. Pehora C, Gajaria N, Stoute M, Fracassa S, Serebale-O'Sullivan R, Matava CT. Are parents getting it right? A survey of parents' internet use for children's health care information. *Interact J Med Res* 2015;4:12.
11. DeLuca JM, Kearney MH, Norton SA, Arnold GL. Internet use by parents of infants with positive newborn screens. *J Inherit Metab Dis* 2012;35:879-84.
12. Knapp C, Madden V, Marcu M, et al. Information seeking behaviors of parents whose children have life-threatening illnesses. *Pediatr Blood Cancer* 2011;56:805-11.
13. Khoo K, Bolt P, Babl FE, Jury S, Goldman RD. Health information seeking by parents in the internet age. *J Paediatr Child Health* 2008;44:419-23.
14. Baker JF, Devitt BM, Lynch S, Green CJ, Byrne DP, Kiely PJ. Internet use by parents of children attending a dedicated scoliosis outpatient clinic. *Eur Spine J* 2012;21:1972-7.
15. Sebelesky C, Voittl J, Karner D, Klein F, Voittl P, Böck A. Internet use of parents before attending a general pediatric outpatient clinic: does it change their information level and assessment of acute diseases? *BMC Pediatr* 2016;16:129.
16. Tuffrey C, Finlay F. Use of the internet by parents of paediatric outpatients. *Arch Dis Child* 2002;87:534-6.
17. Dhillon AS, Albersheim SG, Alsaad S, Pargass NS, Zupancic JA. Internet use and perceptions of information reliability by parents in a neonatal intensive care unit. *J Perinatol* 2003;23:420-4.
18. Plantin L, Daneback K. Parenthood, information and support on the internet. A literature review of research on parents and professionals online. *BMC Fam Pract* 2009;10:34.
19. Kozinets R.V. The field behind the screen: Using netnography for marketing research in online communities. *J Marketing Res* 2002;39:61-72.
20. Varnalı K. Dijital kabilelerin izinde: sosyal medyada netnografik araştırmalar, The trace of digital tribes: netnographic research in social media in: Akdoğan S (ed).1 st ed. İstanbul, Mediacat, 2013.
21. Mortara A, Ironico S. Deconstructing emo lifestyle and aesthetics: a netnographic research. *Young Consumers* 2013;14:351-9.
22. Bratucu R, Gheorghe I, Radu A, Purcarea V. The relevance of netnography to the harness of Romanian health care electronic word-of-mouth. *J Med Life* 2014;7:363-7.
23. Dahan GS, Levi E. Netnografya: Sosyal mecralarda tüketici araştırmaları üzerine yeni bir metot. *Gümüşhane University Journal Of Communication* 2012:1.
24. Suzuki LK, Kato PM. Psychosocial support for patients in pediatric oncology: the influences of parents, schools, peers, and technology. *J Pediatr Oncol Nurs* 2003;20:159-74.
25. Klassen AF, Raina P, McIntosh C, et al. Parents of children with cancer: Which factors explain differences in health-related quality of life. *Int J Cancer* 2011;129:1190-8.
26. Yeh CH, Lee TT, Chen ML, Li W. Adaptational process of parents of pediatric oncology patients. *Pediatr Hematol Oncol* 2000;17:119-31.
27. Henström M, Hanglund K, Skolin I, Von Essen L. Distressing events for children and adolescents with cancer: child, parent, an nurse perceptions. *J Pediatr Oncol Nurs* 2003;20:120-32.
28. Hildenbrand AK, Clawson KJ, Alderfer MA, Marsac ML. Coping with pediatric cancer: strategies employed by children and their parents to manage cancer-related stressors during treatment. *J Pediatr Oncol Nurs* 2011;28:344-54.
29. Eiser C, Eiser JR, Stride CB. Quality of life in children newly diagnosed with cancer and their mothers. *Health Qual Life Outcomes* 2005;3:29.
30. Hung JW, Wu, YH, Yeh CH. Comparing stress levels of parents of children with cancer and parents of children with physical disabilities. *Psycho-Oncology* 2004;13:898-903.
31. Kazak AE, Brier M, Alderfer MA, et al. Screening for psychosocial risk in pediatric cancer. *Pediatr Blood Cancer* 2012;59:822-7.