Use of communication technology by mothers of children with oncological diseases

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Abstract

We investigated the use of communication technology, specifically having internet and use of internet for receiving medical information, by mothers of children with oncological diseases. A total of 52 mothers were included in this survey. 21 subjects were in Group 1 (≤30 years old), 21 subjects were in Group 2 (31–40 years old), and 10 subjects were in Group 3 (41–50 years old). A questionnaire related to the use of communication technology was given to all subjects. In Groups 2 and 3, the rates of having a computer (90.0% and 85.7%) and internet access (80.0% and 71.4%) were higher than those in Group 1. A total of 47.6% to 70% of mothers had acquired information before visiting the physician, the sources of which were the internet (38.1%–50.0%) and "someone who experienced the same condition previously" (20.0–23.8%). Physicians' personal sites and internet forums were the most frequently visited web sites. The most frequently accessed information source after learning about a child's illness other than a physician was also the internet (33.3–57.1%). The mothers in Group 2 used knowledge gain from the internet to ask more informed questions to physicians regarding treatment planning (42% of mothers in Group 2). For all groups, the most reliable source in terms of accuracy of information was the physician (90.5–100.0%). We conclude that mothers of children with oncological diseases use the internet to obtain more information about a child's illness. Physicians are still the most reliable source of information.

Key Words: communication technologies, internet, computer, information sources

Introduction

Childhood cancer affects not only the child, but also his or her family (Kerr et al, 2007). Kazak et al. (2005) stated that the psychological impacts of childhood cancer in parents and children are post-traumatic stress symptoms, depression, anxiety, and stress. These symptoms have a negative impact on the child's social, emotional, and behavioral adjustment to the diagnosis and treatment of cancer as well as the parents' participation and compliance with their child's complex health care needs. Caring for a child with cancer involves psychosocial and behavioral issues and is a complex process for parents (Holm, Patterson & Gurney, 2003). The life-threatening nature of the disease, prolonged treatment period, pain experiences, complications, and unpredictability of illness cause emotional distress in parents (Sloper, 2000).

The care of patients now almost inevitably involves many individuals, who must share patient information and discuss patient management. As a consequence, there is increasing interest in and use of information and communication technologies to support health services. Indeed, if information is the lifeblood of healthcare, then communication systems are the heart that pumps it. Yet, although there is significant discussion of and investment in information technologies, communication systems receive much less attention (Touissant & Coiera, 2005).

The interruptive nature of hospitals is a result of the communication practices and systems in place in these organizations. For example, external telephone calls are a major source of interruption in emergency rooms, especially if clinical staff members are expected to suspend their current tasks to handle the calls. A simple organizational change such as the introduction of a dedicated communications clerk who fields all incoming calls has the potential to significantly reduce the communication load on clinical staff (Coiera, 2006).

In addition, despite increased access to technology, other forms of communication are essential to ensure that everyone, including non-Web users, is able to obtain, process, and understand health information to make good health decisions. These include printed materials, media campaigns, community outreach, and interpersonal communication.

In the present study, we investigated the use of communication technology, specifically having internet and use of internet for receiving medical information, by mothers of children with oncological diseases. Necessary information was obtained via a custom-made questionnaire. Our hypothesis is the mothers of children with oncological diseases may use internet and communication technology to have information about their children's oncological diseases.

Materials and Method

This survey was conducted in 9 Eylül University, Pediatric Oncology Department from August to September 2013.

Participants

The study group comprised 52 mothers of children with oncological diseases that were admitted to the Pediatric Oncology Department. There were 21 subjects in Group 1 (≤30 years old), 21 subjects in Group 2 (31–40 years old), and 10 subjects in Group 3 (41–50 years old). The mothers were asked to complete a questionnaire (see Appendix 1) related to their use of communication technologies. In this questionnaire, demographical information including age, education and job of the mothers were asked initially. Later, the questions were related to use of communication technologies: Having computer or internet connection, knowing to use the internet, internet usage time per day, purpose of internet usage, having information about child's illness, visited web sites and trusted information sources were also asked.

All steps of the survey were planned and carried out according to the principles outlined in the Declaration of Helsinki (2000). Participants were included after verbal approval for entering the study.

Statistical analysis

SPSS 16.0 was used for statistical analysis. The chi-square test was conducted, and the level of significance was set at $p < 0.05$.

Results

There were 21 subjects in Group 1 (≤30 years old), 21 subjects in Group 2 (31–40 years old), and 10 subjects in Group 3 (41–50 years old). Most subjects in Group 1 had graduated from secondary school (71.5%). In Group 2, 42.9% of the subjects graduated from a university. In Group 3, 40.0% of the subjects graduated from both secondary school and a university. The chi-square test revealed no differences in education level among the groups ($p = 0.332$, $X^2 = 0.940$). In all groups, most of the mothers were housewives (81.0%, 57.1%, and 60.0%, respectively) ($p > 0.05$, chi-square test).

In Groups 3 and 2, most of the mothers owned a computer (90.0% and 85.7%, respectively) and had internet access (80.0% and 71.4%, respectively). In Group 1, 42.9% and 38.1% of the mothers owned a computer and had internet access. The proportion of mothers who owned a computer in Group 1 was lower than in Groups 3 and 2 ($p<0.05$). There were no significant differences in internet access among the groups ($p > 0.05$). The internet knowing ratio was 80.0%, 81.0%, and 66.7% in Groups 3, 2, and 1, respectively ($p > 0.05$). The daily internet use duration was 1 to 2 h (50% in Group 3, 33.7% in Group 2) and ≤1 h (42.9% in Group 1) ($p > 0.05$) (See Table 1).

Table 1 *Technology using ratio of the groups*

		Group 1		Group 2		Group 3		
		n	%	n	%	n	%	p
Having computer	Yes	9	42,9	18	85,7	9	90,0	P=0.002
	No	12	57,1	3	14,3	1	10,0	X2=9,312
Having internet	Yes	8	38,1	15	71,4	8	80,0	P=0.067
	No	13	61,9	6	28,6	2	20,0	X2=3,363
Knows internet usage	Yes	14	66,7	17	81,0	8	80,0	P=0.337
	No	7	33,3	4	19,0	2	20,0	X2=0.924
Internet usage duration (daily)	None	7	33,3	4	19,0	2	20,0	P=0.133
	≤1 h	9	42,9	6	28,6	2	20,0	X2=2,259
	1-2h	3	14,3	7	33,3	5	50,0	
	3-4h	1	4,8	3	14,3	0	0,0	
	≥5 h	1	4,8	1	4,8	1	10,0	

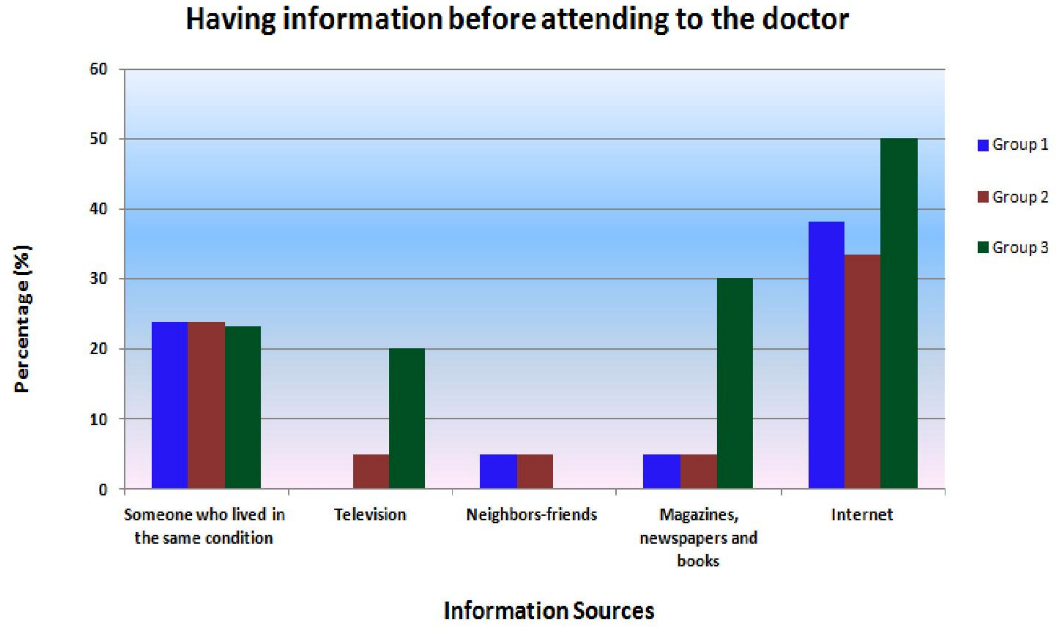
The aims for internet use in the three groups were as follows:

1. Games: 23.8% in Group 2 and 20.0% in Group 3 used the internet to play games (p > 0.05). Shopping: 20.0% in Group 3 and 19.0% in Group 2 used the internet for shopping (p > 0.05). Chatting: 28.6% in Group 2 and 10.0% in Group 3 used the internet for chatting (p > 0.05). Research and obtaining information: 70.0% in Group 3 and 57.1% in Groups 1 and 2 used the internet for this purpose (p > 0.05).
2. Banking: 30.0% in Group 3 and 14.3% in Group 2 used the internet for banking; in Group 1, none of the mothers used the internet for banking (p < 0.05).
3. Watching movies: 10.0% in Group 3 and 9.5% in Group 2 used the internet for watching movies (p > 0.05).
4. Reading the newspaper: 30.0% in Group 3, 19.0% in Group 2, and 14.3% in Group 1 used the internet to read the newspaper (p > 0.05).

Having information before visiting a physician

A total of 70.0% of subjects in Group 3, 52.4% in Group 2, and 47.6% in Group 1 had accessed information before visiting a physician (p > 0.05). The information sources were shown in Figure 1. Except television; there were no significant differences between Groups 1-3 (p > 0.05). Television sources were used in Groups as: Group 1 (0.0%), Group 2 (4.8%), and Group 3 (20.0%) (p < 0.05).

Figure 1 *The condition of having information before attending to the doctor in groups 1-3*



Web sites visited in relation to the children's disorders shown that there were no significant differences between groups 1-3 except Private hospitals' sites (p > 0.05). Visiting ratio of the Private hospitals' sites were detected as: Group 1 (4.8%), Group 2 (0.0%), and Group 3 (0.0%) (p <0.05).

Information sources other than a physician after learning of their child's illness

A total of 42.9% of the subjects in Group 1, 38.1% in Group 2, and 70.0% in Group 3 obtained information from sources other than a physician after learning of their child's illness (p > 0.05). There were no significant differences between information sources of the groups 1-3 (p > 0.05**).**

Thoughts about the helpfulness of information obtained from the internet for treatment planning

1. To ask more informed questions of the physician which contributes to treatment planning: Group 1 (14.3%), Group 2 (42.9%), and Group 3 (20.0%) (p > 0.05).

2. To see if the information obtained from the internet and that given by the physician overlaps: Group

1 (19.0%), Group 2 (14.3%), and Group 3 (10.0%) (p > 0.05).

3. Do not think it would be of any benefit: Group 1 (0.0%), Group 2 (4.8%), and Group 3 (0.0%) (p > 0.05).

If information obtained from the internet and that given by your physician about your child's disease differ, which one do you feel more confident about?

The differences among the three groups were not statistically significant (p > 0.05).

1. I trust our physician: Group 1 (61.9 %), Group 2 (71.4%), and Group 3 (40.0%)

2. Primarily rely on the information from the internet: Group 1 (14.3%), Group 2 (14.3%), and Group 3 (40.0%)

3. I think both of them are equal: Group 1 (23.8%), Group 2 (14.3%), and Group 3 (20.0%)

Do you use non-drug treatment methods (nettle seeds, blackberry root, centaury, oil, etc.) based on information obtained from the internet related to your child's disease?

A total of 47.6% of subjects in Group 1, 28.6% in Group 2, and 30.0% in Group 3 were using non-drug treatment methods. There were no significant differences among the groups (p > 0.05).

Most reliable sources in terms of accuracy of information: First-order response regarding most reliable sources

1. Internet: Group 1 (42.9 %), Group 2 (23.8%), and Group 3 (30.0%) (p > 0.05).
2. Television programs: Group 1 (0.3%), Group 2 (4.8%), and Group 3 (0.0%) (p > 0.05).
3. Newspapers and magazines: Group 1 (0.0%), Group 2 (14.3%), and Group 3 (0.0%) (p > 0.05).
4. Other parents with experience of a child with a similar disease: Group 1 (4.8%), Group 2 (0.0%), and Group 3 (0.0%) (p > 0.05).
5. Your physician: Group 1 (90.5%), Group 2 (95.2%), and Group 3 (100.0%) (p > 0.05).

Most reliable internet sources in terms of accuracy of information: First-order response regarding most reliable sources

1. Sites of public hospitals: Group 1 (33.3%), Group 2 (19.0%), and Group 3 (30.0%) (p > 0.05).
2. Sites of private hospitals: Group 1 (4.8%), Group 2 (19.0%), and Group 3 (0.0%) (p > 0.05).
3. Physicians' personal sites: Group 1 (28.6%), Group 2 (38.1%), and Group 3 (40.0%) (p > 0.05).
4. Forums: Group 1 (0.0%), Group 2 (4.8%), and Group 3 (0.0%) (p > 0.05).
5. Association sites: Group 1 (0.0%), Group 2 (0.0%), and Group 3 (20.0%) (p > 0.05).

Discussion

Cancer is a chronic and life-treating illness that affects the lives of both affected children and their parents. The incidences of childhood cancers in Europe and the US are 138.5 and 169 per million, respectively (National Cancer Institute, 2011; Stiller et al, 2006). The incidence in Turkey is 115.6 per million (Mortality Statistics in Province and District Centers, 2002). Childhood cancers are rarer than adulthood cancers, but they comprise less than 1% of all cancers each year (National Cancer Institute, 2011). However, the survival rate of childhood cancer has increased considerably in response to advances in the medical treatment of cancer in the past few decades (Robison et al, 2009). Therefore, improving the quality of life and sense of control of the child and family is essential during this period.

All people have some ability to manage their health and the health of those they care for. However, with the increasing complexity of health information and health-care settings, most people need additional information, skills, and supportive relationships to meet their health needs (Health Communication and Health Information Technology, 2013). Parents' views about the decision-making process were categorized into three groups: 1) the physician has authority, 2) the parent has authority, or 3) the parent and physician share their opinions and make a decision together (collaborative). The diagnosis and treatment of childhood cancer are new experiences that dramatically change families' lives. Parents require support as they seek information and make decisions during this process. The findings from this study reflect the need for such support during the diagnosis and treatment period. Parents' information and decision needs can change over time, so it is important to continue to assess those needs throughout the process, especially at crisis points (Kilicarslan-Toruner & Akgun-Citak, 2013).

Undergoing cancer treatment is confusing and frightening for both children and their families. A parent may break down or become angry when trying to discuss his child's condition. They must also put their personal feelings and circumstances aside. If they're having a bad day, for example, it must be remembered that the parent or child in front of them is likely facing a much worse situation than they are. In addition, the patients and families from other countries or cultures, and must be patient if these cultural differences hinder communication (Williams, 2016).

Based on pediatric patients' and parents' perspectives on quality of care, improvements are needed in the quality of information and access to services (Hanberger, Ludvigsson & Nordfeldt, 2006). Social support is important for psychosocial adaptation when living with a pediatric chronic disease (Nicholas et al, 2012). Recent research demonstrates how online support groups may contribute to patient empowerment (van Uden-Kraan et al, 2008).

Walsh, et al. (2014) aimed to prevent failures in communication between clinicians and families and between families at home about home medication use, as well as the associated medication errors. They successfully partnered with parents, clinicians, and IT experts to develop Home Medication Support (HoMeS), a family-centeredWeb-based intervention. HoMeS includes a medication calendar with decision support, a communication tool, adverse effect information, a metric conversion chart, and other information. The 15 families in the feasibility study gave HoMeS high ratings for acceptability and usefulness. Half recorded information on the calendar to indicate to other caregivers that doses were given; 34% brought it to the clinic to communicate with their clinician about home medication use. They reported that there was no change in the rate of medication errors in this feasibility study.

The use of new information and communication technologies is a new but growing subject. It shows promise regarding improved diabetes care in general (Bellazzi et al, 2002; Jackson et al, 2006). At least among patients with poor metabolic control, greater use of health care services, higher motivation, and/or less experience with diabetes treatment seem to be of benefit, although few significant long-term effects on the main outcomes have been shown. Positive effects on knowledge and psychosocial well-being have been found as a result of internet educational interventions in adolescents with diabetes (Cooper, Cooper & Milton, 2009).

From this viewpoint, we designed a study to investigate the use of communication technologies by mothers of children with cancer using a custom-made questionnaire. In the present study, most of the mothers were housewives. In Groups 2 and 3, the rates of owning a computer (90.0% and 85.7%, respectively) and having internet access (80.0% and 71.4%, respectively) were higher than those in Group 1. The higher rate of internet use may be expected in the youngest group. However, the opposing result may be explained by their economic insufficiency at such young ages. The most common purposes of internet use were research and obtaining information (70.0% of subjects in Group 3 and 57.1% in Groups 1 and 2). The other purposes, such as playing games, shopping, banking, and reading the newspaper, were reported less frequently (20.0%–30.0%). A total of 70.0% of subjects in Group 3, 52.4% in Group 2, and 47.6% in Group 1 had accessed information before visiting the physician, the sources of which were the internet (38.1%–50.0%) and "someone who had lived with the same condition" (20.0%–23.8%). The rate of internet use was highest in Group 3 (50.0%). Physicians' personal sites were the most frequently visited web sites (19.0% in Group 1, 23.8% in Group 2, and 10.0% in Group 3), followed by internet forums (14.3% in Group 2 and 10.0% in Group 3).

When we asked about information sources other than a physician used by parents after learning of their the child's illness, 42.9% of subjects in Group 1, 38.1% in Group 2, and 70.0% in Group 3 mentioned that they had obtained information from a source other than a physician after learning about their child's illness. Information sources were the internet in the first order [33.3% in Group 1, 57.1% in Group 2, and 30.0% in Group 3) and "someone who lived with the same condition" in the second order (33.3% in Group 1 and 28.6% in Group 2). The usefulness of information obtained from the internet for planning the treatment of their children was principally "To ask more informed questions of the physician, which contributes to treatment planning" (14.3% in Group 1, 42.9% in Group 2, and 20.0% in Group 3).

When we asked, "If information learned from the internet and given by your physician about your child's disease differ, with which do you feel more confident?", the main answer is to trust the physician. The trust rate was 71.4% and 61.9% in Groups 2 and 1, respectively; however, it was lower in Group 3 (40.0%). We concluded that as the mothers aged, their trust decreased due to their prior life experience. Moreover, in all groups the most reliable source in terms of accuracy of information was the physician (90.5–100.0%). The differences between answers may be related to the mothers in Groups 3 not clearly understanding the question. In the health section, physicians were stated to be the most trusted sources.

In our study, 28.6% to 47.6% of mothers used non-drug treatment methods (nettle seeds, blackberry root, centaury, oil, etc.) for their child, based on information obtained from the internet. This indicates that information obtained on the internet should be used with caution.

Kilicarslan-Toruner and Akgun-Citak (2013) found that parents first received information about their child's illness from medical physicians and nurses. Other information resources for parents were the internet, television, friends, and parents of other children who were staying in the hospital. Parents stated two stages of information needs. In the first stage, they emphasized their information needs after learning of their child's diagnosis. Their greatest information needs pertained to the therapy process, prognosis, illness, therapy complications, caring for the child, and approaches to the child. The second stage concerned the information requirements during the illness and treatment. They stated that they wanted to gain knowledge regarding the prognosis, how to approach their child, how to care for their child, treatment complications, coping skills, new therapies, illness, and medications.

People's information needs are correlated with their education level, effects of treatment, and length of interaction and communication with health-care providers (Cegala et al, 2008; Han et al, 2010; Nagler et al, 2010). In our study, parents identified inadequate information, communication/interest, and time since diagnosis as factors that prompted them to seek information. When parents think that the information and care they are receiving is inadequate, they are more likely to seek additional information. This behavior may be associated with education and experience. It has been shown that communicating well with parents and providing clear and adequate information that meets their needs facilitates their information-seeking behavior.

The increase in online health information and services challenges users with limited literacy skills or limited experience using the internet. For many of these users, the internet is stressful and overwhelming, even inaccessible. Much of this stress can be reduced through the application of evidence-based best practice with a user-centered design (Department of Health and Human Services (US), Office of Disease Prevention and Health Promotion).

Ideas about health and behaviors are shaped by the communication, information, and technology with which people interact every day. Health communication and health information technology are central to health care, public health, and the way our society views health. These processes make up the context and the methods by which professionals and the public search for, understand, and use health information, significantly impacting their health decisions and actions (Health Communication and Health Information Technology, 2013).

Few studies have offered web-based interventions simultaneously to patients and their family caregivers. More in-depth information regarding patients' and caregivers' satisfaction with web-based programs and how they can be improved is needed. Dyadic web-based interventions are an innovative method of providing information to both patients and caregivers and promoting their dyadic communication (Yoon 2013).

The success of medical treatment depends not simply on the treatment alone; the family's cooperation is also a crucial factor (Yeh 2002). Parents' understanding of the diagnosis and treatment facilitates their successful involvement in their child's care by increasing their psychological and emotional readiness (Holm, Patterson & Gurney, 2003). Parents must be given information more than once during diagnosis and treatment because they may comprehend only small amounts of information during these stressful periods (Santacroce 2002). According to Kästel, Enskär & Björk (2011), the families' information-taking preferences must be considered, and instructions that are more distinct must be given to assist parents in coping with the situation.

The internet remains a rather new tool in patient education, and its implementation in routine care is not rapid (Nordfeldt, Hanberger & Berterö, 2010; Nordqvist et al, 2009). For practitioners trained in a culture of care with secrecy and strong restrictions regarding dissemination of patients' data, the global progress towards openly sharing personal health information on the internet (Greene et al, 2011) initially might seem somewhat uncomfortable and confusing. However, provided that practitioners can control and/or monitor the information content of the portal, their motivation to use it in their daily practice will likely increase over time.

We conclude that mothers of children with oncological diseases use the internet to obtain more information about a child's illness. Physicians are still the most reliable source of information. Being able to ask more informed questions was the main purpose of internet use by these mothers. The use of non-drug treatment methods shows that information from the internet should be obtained and used carefully.

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Conflict of interest

The authors declare that there is no conflict of interest.

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