

## RESEARCH ARTICLE

# Exploring Communication Difficulties in Pediatric Hematology: Oncology Nurses

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### Abstract

**Background:** Communication plays an important role for the well being of patients, families and also health care professionals in cancer care. Conversely, ineffective communication may cause depression, increased anxiety, hopelessness and decreased of quality life for patients, families and also nurses. **Objective:** This study aimed to explore communication difficulties of pediatric hematology/oncology nurses with patients and their families, as well as their suggestions about communication difficulties. **Materials and Methods:** It was conducted in a pediatric hematology/oncology hospital in Ankara, Turkey. Qualitative data were collected by focus groups, with 21 pediatric hematology/oncology nursing staff from three groups. Content analysis was used for data analysis. **Results:** Findings were grouped in three main categories. The first category concerned communication difficulties, assessing problems in responding to questions, ineffective communication and conflicts with the patient's families. The second was about the effects of communication difficulties on nurses and the last main category involved suggestions for empowering nurses with communication difficulties, the theme being related to institutional issues. **Conclusions:** Nurses experience communication difficulties with children and their families during long hospital stays. Communication difficulties particularly increase during crisis periods, like at the time of first diagnosis, relapse, the terminal stage or on days with special meaning such as holidays. The results obtained indicate that pediatric nurses and the child/family need to be supported, especially during crisis periods. Feeling of empowerment in communication will improve the quality of care by reducing the feelings of exhaustion and incompetence in nurses.

**Keywords:** Communication difficulties - cancer communication - pediatric hematology/oncology nursing - empowerment

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### Introduction

Diagnosis and treatment of cancer in children create a challenging situation, with uncertainty causing distress in both children and their parents (Pai et al., 2007; Björk et al., 2009). Communication plays an important role for the well being of patients, families and also health care professionals. It is important for all healthcare professionals to have effective communication skills to evaluate and improve oncology care (Maskor et al., 2013).

Nurses can identify the psychosocial needs of patients and families, enhancing their psychosocial adaptation and maintaining the quality of life by effective communication. It's also important for improving autonomy and participation in care and treatment of children and parents. (Wenzel and Shaha, 2008; Lambert et al., 2009).

Conversly, ineffective communication may cause depression, increased anxiety, hopelessness and decreased of quality life of patients. Ineffective communication have an effects on nurses who care the paediatric oncology patients and families too. Stress and burnout among paediatric oncology nursing have been linked to feelings of having insufficient communication skills and expectations of

a negative outcome after communication with the patients (Tay et al., 2012).

Caring for patients with chronic or life-threatening illnesses, communication and relationships with patients and other healthcare professionals are common themes that cause concerns in oncology nurses (Dowling, 2008; Van Rooyen et al., 2008). Palsson and Norberg (1995) identified several concerns: becoming too close to patients and their families; feeling powerless; feeling disgust, shame, and guilt; relationships with patients' families; and communication gaps. Oncology nurses have multiple responsibilities and roles in cancer-related care. Competencies in oncology include holistically assessing patients and families, developing skills in communication, building relationships and problem-solving (Fillion et al., 2006; Mascor et al., 2013).

When we examined the reasons of the communication difficulties some factors belongs to nurses. Researches indicated that nurses inhibit communication with patients when they have difficulties handling emotionally charged topics such as death and dying. Empowerment of nurses' communication who are at the foreground of health care is essential in enhancing effectiveness in work,

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managing stress, the quality and safety of patient care, cost effectiveness, and the retention of nurses (Wilkinson et al., 2008; Steward et al., 2010). Feeling empowerment in communication is related to individual factors such as nurses' skills, stress and job satisfaction (Lautizi et al., 2009).

The purpose of this study was to explore the communication difficulties of pediatric hematology/oncology nurses with patients and their families, as well as their suggestions about communication difficulties. The specific objectives of the study were: *i*) What are the communication difficulties of pediatric hematology/oncology nurses with the patients and their families in their care? *ii*) How do these communication difficulties affect pediatric hematology/oncology nurses? *iii*) What are the pediatric hematology/oncology nurses' suggestions about communication difficulties regarding themselves?

## Materials and Methods

### Sample and study design

This descriptive qualitative study was conducted in a pediatric hematology/oncology hospital in Ankara, Turkey, in December 2011. The hospital has two hemato-oncology wards with 51 beds and one hematopoietic stem cell transplantation unit (HSCTU) with 10 beds. A total of 55 staff nurses have been working in the wards, which included 28 staff nurses in the hemato-oncology wards and 27 staff nurses in the HSCTU. Nurses are working in two shifts: 08.00 am - 04.00 pm and 04.00 pm - 08.00 am. Most of the diagnoses in the wards were leukemia, lymphoma, neuroblastoma, thalassemia and aplastic anemia. The average hospitalization days were 2 months for HSCT patients and 20 days for the ward patients. The nurses had participated in orientation programs 15 days after starting their new job at the hospital. On-site workplace training was 1 hour per week for nurses. There was not any education program regarding communication for staff nurses.

Qualitative data were collected from 21 pediatric hematology/oncology nursing staff by using the focus group technique, and they were divided into three groups.

Before the interviews, a short data form was used to determine the descriptive characteristics of the nurses, including age, education and experience in nursing and pediatric hematology/oncology wards. The nurses' mean age was 26.80±3.5 years and mean experience 4.47±3.99 years in the profession.

Pediatric nurses were selected based on voluntarism, availability during shifts and, who expressed living communication difficulties with children and families. The focus group sizes varied from 6 to 8 participants. Three semi-structured open-ended questions were used to drive the interviews: *i*) What kinds of communication problems do you have with children and their families in pediatric hematology/oncology clinics? *ii*) How do these communication difficulties affect you? and *iii*) How would you feel empowered against having communication difficulties? Qualitative data were collected through interviews in a quiet, private area in the hospital's meeting rooms. Sessions lasted approximately 1 hour. The first

author moderated the focus group by semi-structured form and made the clarification of the topics by sub-questions. The second author observed and noted the main topics of conversations. Before ending each interview, main topics were reviewed with the group.

### Data analysis

The semi-structured focus group interviews were audiotaped and transcribed verbatim. The transcript subsequently was printed for further manual analysis. Content analysis was used to assess the data (Elo and Kyngas, 2008). This process includes three steps: *i*) Open Coding, transcripts were coded line-by-line to facilitate the discovery of underlying meanings. Similar expressions were grouped together; patterns of experience were identified and labeled. The first and second authors did the data analysis independently and identified themes separately. They then compared and determined the final themes; *ii*) Creating Categories, researchers came to a decision as to which things to put in the same category; and *iii*) Abstraction, each category was named using content-characteristic words. Subcategories, with similar events and incidents are grouped together as categories,

Consistency was assured by subjecting the data and findings to confirmation or disconfirmation by two objective peer researchers who were experienced in the field of qualitative research.

### Ethical considerations

The study was approved by the Baskent University Social and Human Sciences Research Committee (Project no: KA11/214) and the Ministry of Provincial Health Services of Turkey. Each participant was invited to read and sign a written consent form if they wished to take part in the study.

## Results

From the analysis, three main categories and seven themes emerged. These are presented in Figure 1. The first category was related to communication difficulties, the

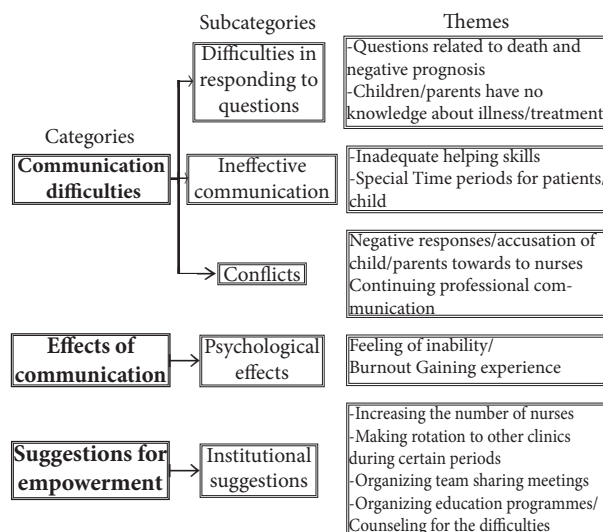


Figure 1. Categories, Subcategories and Themes of the Study

second involved the effects of communication difficulties on the nurses, and the third category was related to suggestions for empowering nurses with communication difficulties, the theme being related to institution issues.

#### Category

**Communication Difficulties:** Three themes were determined in this category. In the first theme, seven nurses stated that they mostly had difficulties in responding to questions, especially those related to negative prognosis and death. Some of the examples given are detailed below.

*"...someone asks about death, for example, and the number of questions about that increases..."*

*"Someone asked me 2-3 weeks after getting the diagnosis "I searched it extensively on the internet. It is said that the mortality rate is low, but is it true? Mortality rates have significantly increased, what would be the result, will I also die?""*

Another type of question that nurses avoided answering was related to the fact that a child and its family were not informed of the disease and therapy.

Two nurses stated that unawareness of the child about the disease and therapy affected their communication with him/her because the child might have rejected the therapy since he/she did not know about his/her disease and he/she could not establish an open communication since he/she asked questions that might not have been answered.

*"...A 17-year-old child, he knows what the oncology service is, he has a computer, internet at hand, but his mother pleads with me not to tell him/her, .....this time the patient rejects the therapy since he does not know the disease, he asks why should they need this, the mother said to him that the lymphatic infection will be treated with antibiotics and then he will go back home. The first question the child asks me is whether infected people stay in this service.... The child eventually realizes the situation, and this hurts his confidence. The child then does not contact his/her family, does not trust us, I means he goes into his own shell ..."*

The second theme related to the communication difficulties experienced by the nurses is ineffective communication. Nurses stated that they have inadequate helping skills especially in managing terminally ill, desperate and depressed patients. They stated that they failed in establishing effective communication with terminally-ill patients and those who rejected therapy, particularly since they did not know how to give hope. Also, most of the nurses who participated in the research stated that most children withdrew themselves from communication when they were in a desperate and depressed mood, avoiding contact with the healthcare team. Nurses thus could not access the child, influencing the motivation of the nurses, who also became desperate and unable to cope with the stress, thereby causing difficulty in working.

*"...they feel great pain during the terminal period, processes of the therapy are severe, adverse effects they experience are also severe, their situation is highly severe, this is the period when we experience the highest degree of trouble, they withdraw themselves from communication ..."*

*to..." "It is a bit easier to calm families when the patient is first diagnosed. There is at least some hope at that stage, but we are dwelled on during the terminal period ...parents expect some hope, they expect someone telling them something good, we do not know how to behave in this situation. The only trouble we experience at that time is to relax that person."*

*"For example, I had great difficulty in taking care of this patient. Therapy is easy if we consider in terms of nursing. They are all the procedures we apply routinely. But I had a serious difficulty, since I had to take care of that patient all the time. The child was very little but I felt like I was talking to an older person. The child had a logical explanation for everything. I sometimes failed in convincing him/her"*

Nurses indicated that they experiences ineffective communication at the times of disease stages and special times. They stated that the patients suffered from a higher degree of difficulties when they were first diagnosed, and during relapse and the terminal stage.

*"This is the case not only for the newly diagnosed, but also for those in the terminal period. They suffer from really severe pains, procedures are severe, adverse effects they experience are also severe, their situation is highly severe. This is the period we experience the highest degree of trouble."*

*"One of the periods when the children reject therapy is during special public holidays. For example, they want to be at home on feast holidays. They reject the therapy, they say let me go, I will not allow for the therapy, these days are highly troublesome..."*

Third theme included in communication difficulties was the conflicts with patients and their relatives. The nurses stated that they suffered conflicts in communications as a result of negative responses given by families about the disease and accusations against the nurses. They thought that the exhaustion felt by families, as well as their lack of support for the child, their disease perceptions and exposure to other families resulted in these conflicts.

*"Interaction between the family and the child frequently occurs just like any other interaction among families. I noticed that the more hopeful the mother is, the higher the compliance of the child to the therapy is. For example, the child immediately participates when I describe the therapy. But when the mother is not hopeful, she confesses some things in advance. The child then reflects this as if he/she feels something from the mother."*

*"They both do not accept their disease and secretly blame us when they have accepted, as if we are the reason for their disease."*

Another reason for the conflicts stated by the nurses is related to the maintenance of professional communication. Two nurses stated that they had difficulties in maintaining professional relations with patients and families, since they had stayed at the hospital for a long time and due to the nursing image they had.

*"Professionalism shifts, for example, they stay at the hospital for 4 months. The mothers get some ideas that we are friends. Sometimes I am shocked by their behavior; they try to join us, they abuse close relations. We cannot make contact with them if we avoid from behaving in such*

a way, there is a fine line ...”

“...I think this is related to their personality. I mean this is not a short period. They behave as if they are at home and they display their real character here. Of course their experiences are difficult, their children are administered many procedures, they do not know the result. Of course all these are not easy, but some people properly perceive this and so everything goes right ....”

#### Category

**Effects of Communication Difficulties:** The nurses said that they mostly experienced psychological effects linked to communication difficulties. The most emphasized effects were that they felt incompetent, experienced exhaustion and tended to avoid communicating with children and families as a consequence. They also reflected on this stress during their private lives.

“One child died recently, just before I bathed, cared, creamed him. Then I thought whether he died because of me, whether I did something wrong. My psychology was really distressed. Actually the child died for a reason completely irrelevant, and he/she died after a few days.”

“Of course it is exhausting. It is impossible not to think about it ...”

“Sometimes parents say you riddled the child with holes, you cannot do this, call the doctor. Then we become more agitated and we are really confused”

“.....we go back home, say we forget but we always feel the stress and reflect on it in our private life”

“We feel bad. It is a sense of incompetence”

One nurse mentioned that the communication difficulties experienced positively affected her and helped gain experience.

“...I love taking care of problematic patients more. This has led me to gain experience. I have worked here for about 2 years. Previously I was telling patients about the problem before the transfer but not paying special attention, not describing in detail. But now I am accustomed by seeing their troubled times, for example, some mucositis occurring after the transfer. Now I feel as if I deliver a speech when I start to take care of newly transferred patients. I tell the families that we will do this in this way etc. I also talk to the child. I now provide more detailed information about patient care”

#### Category

**Suggestions for Communication Difficulties:** When the nurses were asked about the suggestions for the the issues of communication difficulties, they usually gave some recommendations oriented to their institution. They suggested increasing the number of nurses working in clinics. They highlighted the fact that communication difficulties mostly arose because they could not allocate sufficient time for patients due to the low number of nurses working in the clinics.

“We believe that we take special care in cases of child patients, the number of nurses is absolutely very low ... I feel as if I am here everyday of the week. We get exhausted from working; we think that we cannot rest, we become mentally depressed. Sometimes we cut off communication with the children. I sometimes think that I will perform the

therapy, who cares about communication ...”

“I think the number of nurses must definitely increase, namely it should be increased in special units like hematology/oncology, the bone marrow unit. If we think about the number of patients per nurse, it is 9. How can I care for 9 children? I cannot look after everyone the same, this is not possible.”

Another recommendation was that nurses should be occasionally sent on rotation in different clinics, since they work in a clinic with a heavy emotional burden.

“I think that being in the same atmosphere all the time also has a negative effect. I think some clinics like intensive care, oncology, exhaust us. Nurses should be shifted to other services after the end of a certain period”

“...I think rotation should be applied in such services. This makes one miserable in the long run. I think that we should stay in these services maximum for one year ...”

Three nurses participating in the research said that regularly organizing team meetings in which the whole healthcare team came together and shared their experiences and feelings would also be beneficial. This would relax and calm nurses by enabling the sharing of their feelings, as well as help the spread of knowledge of what to do in difficult situations.

“...communion meetings form opinions at least on the issue of what to do. They would be effective if they were held regularly but useless if they are held just 1-2 times ...”

“...will these meetings just be composed of nurses or would doctors and other health care team members also attend?”

The last recommendation concerned training programs on the issue of communication skills, and advice on how to cope with difficult or intensely emotional cases.

“...our team may receive regular training on this issue in some topics like how to communicate, communication techniques. This could be provided to us and some moral support may be provided to us too. This unit has been open for about 2 years, 4-5 patients have died. We have all cried, we feel that we sometimes veer away from professionalism... Emotion management, anger management could be provided to us. We direct our anger to the team members. There may be a replacement and for example we feel very exhausted when we go home ...”

“I think there should be someone providing psychological assistance in every clinic because we cannot cope with every problem ...”

## Discussion

Communication difficulties are one of the major concerns of pediatric oncology nurses. In this study, nurses stated communication difficulties as three categories. The most emphasized problem in the communication difficulties experienced by the nurses was in answering the questions of patients and their relatives. They stated that questions about negative prognosis and death were especially difficult, as well as those arising from when the child and/or family were not informed about the disease and therapy. In the study of McLennon et al. (2013) the oncology nurses expressed the need for more

education about how to communicate in prognosis-related discussions with the patients. Earlier studies in the literature have focused on fundamental communication skills of nurses, but not on the identification of the communication difficulties experienced. In one study found on this issue, Sivesind et al. (2003) reported that nurses had the most difficulty in dealing with deaths in oncology patients. In another study, Klassen et al. (2012) gave the opinions of healthcare staff working with cancer children and their families, demonstrating that nurses had problems in responding to parents with negative information about the disease, causing them stress. This conclusion reported by Klassen et al. (2012) is similar to our finding using information from an End-of-Life Nursing Education Consortium attended by 333 nurses, discussed that nurses mostly had problems in communicating with patients and their relatives during palliative care. Indeed, the pediatric nurses in this study said that they experienced the greatest communication difficulties during cases of poor prognosis and terminally-ill patients.

Malloy et al. (2010) mentioned that nurses with less experience (2-10 years) had a greater level of difficulty in communicating bad news to patients and their relatives than experienced nurses. This is consistent with the findings in our study, in which less experienced nurses had problems regarding this issue.

Another communication difficulty concerned ineffective communication between the nurses and the patients and their relatives. The nurses identified ineffective communication reasons as their inability to manage emotions like desperateness, insufficient assistance skills, difficulty in coping with stress and finally, an insufficient number of nurses and the inability to allocate sufficient time for communication due to the workload.

Zwaanswijk et al. (2011) reported in their study using pediatric oncology patients, families and survivors that only 16.5% of the attendees felt that the healthcare team established effective communication. This is a considerably low ratio and supports our research findings. Tay et al. (2012) described the factors affecting communication between nurses and cancer patients as those relating to the patient, the environment and the nurses. Factors associated with the nurses included insufficient communication skills, working in a job-oriented manner and restriction of communication with patients due to the fear of death. The nurses in our research also felt that they could not spend time communicating with patients due to an insufficient number of nurses and that they could only manage the physical care and therapies of the patients.

Another difficulty experienced by the nurses was conflicts with the patients and their relatives. One of the reasons of conflicts is the negative feelings of nurses about the disease and prognosis. So, they can reflect the work stress on patients and families. This finding indicates that good communication skills of the nurses alone are not sufficient in communicating with patients and their relatives; nurses should be aware of their negative feelings and their effects, and should have skills to manage their own stress.

The reasons given by the nurses for the conflicts included angry attitudes of the patients and their relatives towards the nurses, responses of the patients and their relatives to the disease and the disturbance in the professional relationship between the nurses and patients due to the long treatment period. These actually resulted from insufficiencies in the communication skills of nurses and their inability to manage the behavior of the patients.

The nurses specified the time periods of communication difficulties as those during the first diagnosis, relapse and terminal periods. This finding supports those in the literature (Tay et al., 2012). Patients and their relatives experienced shock and denial, as well as trouble understanding what was happening. Their desperateness increased during relapse periods, on special days and in cases of bereavement in the clinic. They required support and assistance from nurses more during the terminal stage. However, these skills were the ones characterized as insufficient by the nurses. Therefore, difficulty was experienced in communication, both on the side of the patients and their relatives, as well as the nurses.

In our study, the nurses stated that communication difficulties led to the feeling of incompetence, exhaustion or difficulties in coping. Hinds et al. (2005) reported that pediatric nurses looking after children with a life-threatening illness such as cancer experienced emotions like a decline in their aims, suffering and a loss in feeling competent. Communication difficulties experienced by oncology nurses may cause them to experience exhaustion, feeling of incompetence or self-actualization (Bressi et al., 2008; Alacacioglu et al., 2009; Girsis et al., 2009; Emold et al., 2011). When we compared our results to those of earlier studies, we found similar trends regarding communication difficulties. According to the literature, positive or negative perceptions caused by communication difficulties like emotional exhaustion, burnout and personal achievement may differ in relation to personal characteristics of the nurses such as age, resistivity and feeling of self-sufficiency in communication and corporate factors (Constantini et al., 1997; Kash et al., 2000; Alacacioglu et al., 2009; Parker et al., 2009; Usta et al., 2012).

Hematology/oncology nurses suggested an increase in the number of nurses, clinical rotation, communion meetings and training programs as recommendations for empowerment in our study. MacKenzie and MacCallam (2009) reported that attendance in in-service training programs and receiving consultancy were essential for nurses undertaking bereavement work in pediatric palliative care services to improve care quality. Communion meetings assist in preventing fatigue by providing support among team members and the opportunity for sharing anxieties (Hinds and Drew, 2005; Hinds et al., 2005). The recommendations provided in this study are consistent with the results of other studies, which indicate that nurses working in a private area must be supported on a corporate basis by means of consultancy, training and staff employment.

The strength of this report is that this is the first qualitative study examining communication difficulties and empowerment perceptions of pediatric hematology/

oncology nurses in Turkey. Cultural differences may affect these issues in pediatric nurses. In the future, different and wider groups should be studied. The results of this study could guide nursing practice in many aspects. Pediatric nurses have difficulties in issues linked to communication, such as initiating and maintaining communication with children with a life-threatening disease and their families, as well as conflicts in communication. It is important that orientation and in-service training of nurses working in such clinics should be supported and regular meetings should be organized in which they share their experiences in a hospital environment.

In conclusion, hematology/oncology diseases, which include chronic or life-threatening illnesses, are challenging both for the child and the family since the treatment process is complicated and long and has many adverse effects. Nurses who provide 24-hour care and are the first point of contact may experience communication difficulties with children and their families during long hospital stays. Communication difficulties particularly increase during crisis periods, like at the time of first diagnosis, relapse, the terminal stage or on days with special meanings such as holidays. The results obtained in this study indicate that pediatric nurses and the child/family need to be supported, especially during these periods. Feeling of empowerment will improve the quality of care by reducing the feelings of exhaustion and incompetence in nurses.

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