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# Communication in pediatric oncology

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# Abstract:

Introduction: Neoplasms are the second most frequent cause of death in the pediatric population. In Poland, approximately 1100-1200 new cases of malignant neoplasms are diagnosed annually. Communication is an extremely important factor in pediatric oncology care. Hence, more and more research on its functions, significance, but also barriers and limitations is being developed.

Material, methods, purpose: The literature published in the PubMed scientific database was searched using the following keywords: communication, pediatrics, oncology in 2016-2022. The aim of this review is to show the barriers, functions, and the importance of communication in pediatric oncology for the therapeutic process.

Results: Communication in pediatric oncology was shown to perform the following functions: building relationships, exchanging information, enabling the family to self-manage, making decisions, managing uncertainty, responding to emotions, providing validation, and supporting hope. The last two functions have not been found previously in adult oncology. It was also noted that high-quality communication is associated with parental peace, increased recognition and confidence in healthcare professionals. Parents who receive understandable prognostic information have found less regret, as well as a desire to maximize time spent together with their child. Moreover, children who participated in the discussions about the disease had less anxiety and greater acceptance of their disease. Research shows communication barriers on many levels, such as: lack of comfort in difficult topics, time pressure, or the lack of a common mental model of the team and excessive demands. However, knowing these limitations is crucial to improving and overcoming these barriers.

Conclusions: Communication in pediatric oncology plays many fundamental roles and constitutes an important aspect of the therapeutic process. Accordingly, it is important to emphasize the development and improvement of healthcare professionals' communication skills. Doctors can use knowledge of communication functions to better understand and fulfill parents' communication needs. Future work should focus on measuring whether clinical teams are fulfilling these functions and developing communication interventions to address these functions.

Keywords: communication, paediatrics, oncology

#### Introduction:

Cancer is one of the most common causes of mortality in the pediatric population, along with trauma and congenital defects. According to the WHO, about 400,000 children and adolescents aged 0-19 develop cancer each year. In high-income countries, more than 80% of children are cured, while in low-income countries this figure is less than 30% [1]. In Poland, 1100-1200 new cases of cancer are diagnosed annually [2]. The most common are leukemias, neoplasms of the central nervous system and lymphomas [3]. Communication is an extremely important factor in pediatric oncology care. Hence, more and more research on its functions, significance, but also barriers and limitations is being developed.

#### Material, methods, purpose:

The literature was searched in the PubMed scientific database published in 2016-2022 using the following keywords: communication, pediatrics, oncology. The aim of this review is to show the barriers, functions, and the importance of communication in pediatric oncology for the therapeutic process.

### Results:

Children with cancer and their families experience great suffering in the course of the disease. Then there are such problems as: disruptions in normal life due to frequent medical visits and hospitalizations, symptoms related to treatment and disease, financial losses related to the disease and treatment, or the uncertainty of living with cancer. A critical factor in alleviating suffering, be it physiological or psychological, is the doctor-family relationship, and communication is the foundation of this relationship.

High-quality communication between patients and physicians can bring important patient care outcomes: better understanding of the disease, more accurate symptom disclosure, better adherence to scheduled treatments, reduced anxiety and mental stress, reduced feelings of abandonment, increased care satisfaction, and a better overall 'cancer experience' [4]. Communication is essential to providing family-centered care and is also important to well-being and health outcomes in pediatric oncology [5,6]. A desire for communication that is honest, sensitive, kind, empathetic and hopeful is noticed in the parents. The statement that parents want honesty and hope shows that hope comes in many forms, and that cure is only one of them [7]. In the review by M. S. Weaver et al. common themes were noted among the patient, parent and physician on end-of-life needs: trust, honest communication, seeking relief, caring for each other. Common priorities in a cancer setting were also highlighted:

access to care, cost analysis, social support, bereavement assistance, symptom assessment and interventions covering both physical and mental symptoms, decision making and overall quality of care [8].

Pediatric palliative care aims to alleviate the suffering and quality of life of children, and to increase support for their families. Its integration with the routine care of pediatric cancer patients has resulted in improved treatment outcomes. High-quality communication can facilitate greater focus on physical, psychosocial and spiritual needs and lead to better outcomes [9].

Despite the growing understanding that communication in healthcare can be optimized to improve patient and family outcomes, approaches to teaching communication in pediatric oncology are largely local, informal, and specific.

#### **Functions**

In the study by B. A. Sisk et al. with 78 parents of children undergoing treatment (30), surviving the disease by the child (27) or mourning (21), 8 communication functions were detected in pediatric oncology: building relationships, exchanging information, enabling the family to self-manage, making decisions, managing uncertainty, responding to emotions, providing validation and promoting hope. The last two functions have not been found previously in adult oncology. "Relationship building" was identified in each transcript and manifested itself as the presence of clinical competence, integrity, care and concern; advocacy; fostering solidarity; and maintaining open and reassuring non-verbal communication. "Information sharing" was also identified in each transcript and has manifested itself as providing consistent, accurate and up-to-date information in an understandable and transparent manner; clarification of the recommendation; meeting unique information needs. "Enabling family self-management" (75/78) involved providing advance guidance, training in technical skills, identifying needs and giving guidance during acute illness. "Providing validation" (65/78) manifested itself as empowering parents as partners and reinforcing beliefs about "good parenting". "Managing uncertainty" (59/78) manifested itself as discovering the unknowns, making reasonable guesses, and providing encouragement. "Reacting to emotions" (55/78) involved anticipating emotional needs and recognizing and / or adjusting to emotions. "Supportive hope" (47/78) manifested itself as highlighting the positives, demonstrating the intention to heal, avoiding false hopes, and diverting towards hopes other than survival. "Decision making" (46/78) was about involving parents, offering feedback, and providing strong recommendations [10].

### **Errors**

Communication errors in pediatric oncology can have negative consequences for patients and their families. In a study analyzing interviews with 80 parents of children with cancer, 76 negative communication experiences were identified. They concerned individual experiences, the team, the organization and the healthcare system. Parents also reported the personal consequences of the communication breakdown, such as: emotional stress, insufficient understanding, decreased trust / confidence, inconvenience, medical damage, decreased emotional support, decreased commitment, false / decreased hope, financial insult, and decreased access to resources. On the other hand, they considered research, confirmation, information, adaptation and support as supportive from clinicians. Moreover, parents also expressed the need to involve them in finding solutions [11]. In the study of D. R. Levine et al. in 129 patients aged 10-18 years and their parents from three cancer centers, it was found that oncologists may not meet the information needs of many patients and their families. It was found that communication could be improved by being more direct as well as by actively discussing emotional symptoms and the impact of cancer on quality of life [12].

#### **Barriers**

A study by Bryan A Sisk et al. on 59 clinicians (doctors, nurses) working in pediatric oncology departments showed many communication barriers at different levels (individual, team, organization, cooperating hospital, community, politics): lack of comfort with difficult topics (individual), cultural differences (individual), lack of a common mental model of the team (team), time pressure (organization), need for boundaries (individual), intimidation or embarrassment of the family

(individual), unclear roles and authority (team), excessive logistic requirements (politics) [13]. In the study by F. Odeniya et al. three barriers were identified: communication challenges in teams due to hierarchy, and also between teams due to incomplete information sharing and unclear who should initiate the discussion about the goals of care; how to involve parents in making decisions about patients; lack of communication education and training [14]. Communication barriers included misconceptions about the cancer, stigma, and hierarchy between parents and service providers. Training for employees and educating the community facilitated communication [15].

## Interdisciplinary team

In the study by A. R. Newman, nurses described little preparation for participation in such difficult interviews. Pediatric oncology nurses must recognize that they are an integral part of prognostic communication [16]. According to A. R. Newman et al. Nurses are often not involved in the disclosure process, which limits the ability of nurses to function fully in their roles and also puts the patient and family at risk. It is necessary to enable nurses to be more active in this process, as well as educate doctors to involve this professional group [17]. K. J. Sawin et al. emphasize that pediatric oncology nurse trainers draw from their own palliative / end-of-life care experience to meet the educational needs of nursing staff and families / patients. Additional resources are needed to support communication training in palliative care as well as national and hospital programs [18]. It has also been noticed that nurses who cooperate with doctors have longer experience or training feel more confident and have more positive experiences in the case of communication related to prognosis [19].

In the study of D. E. Greatz et al. 174 doctors, 60 nurses, 20 psychosocial service providers and 2 other employees assessed in the survey that interdisciplinary care (which supports high-quality cancer care and the effective use of limited resources) benefits both team members (95%) and patients (96%) [20].

Pediatric patients are at high risk of deterioration of health and require frequent interdisciplinary communication to ensure high-quality care. PEWS are pediatric early warning systems and are used by hospitals to reduce deterioration of health. They have been found to improve interdisciplinary communication by empowering those providing bedside services. Understanding contextual elements is integral to optimizing PEWS and improving pediatric oncology outcomes in hospitals at all resource levels [21].

A laboratory pharmacogenetic test (LDT) can diagnose difficult-to-treat brain tumors and stratify children based on their ability to respond to available treatments. In a study by C. Longo et al. An explanation of the risks, benefits, and accuracy of LDT was considered necessary for parents. When a diagnosis or prognosis was made based on this test, parents appreciated the honesty, empathy, and clarity of communication. They also asked for results and treatment options to be presented impartially in several meetings. This communication allowed enough time to understand messages, even catastrophic ones [22].

Action is needed to improve communication, but education, while important, is often insufficient to bring about a lasting behavior change. B. A. Sisk et al. suggest that interventions that use multimodal approaches to target multiple behavioral domains are needed to overcome communication barriers. For example, an intervention can solve problems with a clinic's workflow while providing training in communication [23].

### Conclusions:

Communication in pediatric oncology plays many essential roles and is an important aspect of the treatment process. Accordingly, it is important to emphasize the development and improvement of healthcare professionals' communication skills. Doctors can use knowledge of communication functions to better understand and fulfill parents' communication needs. Future work should focus on measuring whether clinical teams are fulfilling these functions and developing communication interventions to address these functions. Medical professionals experience communication barriers on many levels, from barriers at the individual level to political barriers. Knowing them can help

clinicians and researchers identify intervention goals to improve family communication experiences in pediatric oncology.

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