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**Ethical Issues of Informed Consent, Communication of Diagnosis and
Prognosis for Children with Incurable Conditions Receiving Palliative
Care**

ABSTRACT

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I. Introduction

Approaching the issues of informed consent, communication and prognosis is of concern to both medical ethicists and those who actually work in the medical field, the subject being all the more sensitive when it comes to children and especially those under care for life-limiting or incurable conditions.

The news of a child's life-limiting illness profoundly affects all aspects of a family's existence, and often parents and children are affected by the way they communicate. They prefer an empathetic mode of communication, want support throughout the course of the illness and want to be told the truth about their child's condition. Partea teoretică a fost structurată în 3 capitole.

Chapter I is a precursor to the concepts, information and studies presented in this thesis.

Chapter II is a synthesis of the information obtained from the literature review and contains information on the concept of informed consent, its history and evolution over time, types of informed consent, children's involvement in decision-making, informed consent in paediatric palliative care and findings from studies on decision-making and informed consent in paediatric practice.

Chapter III presents the most important information from the literature on communicating the diagnosis of an incurable condition in children, the approach to disclosure of the diagnosis by professionals over time, the particularities of end-of-life communication in paediatrics, the guidelines and protocols used in communication and the findings of studies on communication in paediatric palliative care.

The special part, chapter IV of the paper is structured in two parts and aimed to conduct a study to evaluate communication in paediatric palliative care.

The first part of the chapter consisted of a quantitative study that aimed to assess communication preferences in paediatric palliative care from two perspectives: one of caregivers of children with incurable conditions and the second of professionals in paediatric palliative care services. The second part of the chapter was about conducting a qualitative study aimed at identifying how healthcare professionals communicate the news of a child's incurable condition to their parents.

II. Informed consent

II.1 Concepts and definitions

Informed consent is seen as a tool when patients/guardians have to decide whether or not to agree to a treatment or participate in a research project. Giving or declining informed consent is seen as an instrument of self-determination and a key tool in supporting or achieving patient autonomy. (Schrems, 2014)

Informed consent is the process by which clinicians obtain patients' permission to perform invasive procedures on them. In many countries it is a legal and ethical prerequisite for competent adults and requires professionals and patients to discuss the risks, benefits and treatment alternatives, patients to weigh them and then make autonomous treatment decisions. (Farrell *et al.*, 2014)

For a paediatric patient, a natural response to the need to make medical decisions is to delegate authority to their parent or guardian. This frequently occurs while providing families with care according to the specifics of the course, treatment and prognosis associated with a child's condition. In this context, even when considered, a paediatric patient's input into medical decision-making can often be secondary. There are also particular situations where the principle of shared decision-making is not applicable, the best known in paediatrics being the situation where there is non-accidental trauma, where a parent or guardian is suspected of abuse. (Santoro and Bennett, 2018)

The American Academy of Pediatrics (AAP) in its statements (1976, 1995 editions) referring to informed consent has stated that obtaining informed permission from parents or legal guardians prior to medical treatment before any medical intervention on pediatric patients has become a standard within the medical system and legal culture. (Katz and Webb, 2016)

II.2 The history of informed consent

From the Hippocratic period (5th-4th centuries BC) until the last century, the doctor-patient relationship was paternalistic and the patient had to conform to the doctors' point of view. (Conti, 2017)

The idea of informed consent is the result of the awareness of the need for a partnership between medical staff and patients in order to avoid abuses in clinical practice and research. Over time, the basis of the idea of informed consent have changed, both because of advances in medicine and because of the type of data that is collected. (Dankar, Gergely and Dankar, 2019)

The practice of obtaining informed consent has its roots in both clinical medical work and biomedical research and proves its usefulness from their perspective. Discussions of disclosure and justifiable non-disclosure have played a significant role throughout the history of medical ethics, but the

term 'informed consent' only emerged in the 1950s. Serious discussions about the meaning and ethics of informed consent did not begin in medicine, research, law and philosophy until around 1972. In the mid-1970s, medical ethics gradually shifted from the physician's or researcher's obligation to disclose information to the patient's understanding of the information and the patient's right to consent to or refuse a biomedical intervention. This change was the real beginning of the implementation of informed consent in medical practice. However, even today, most consents may not be sufficiently informed to constitute informed consent. (Beauchamp, 2011)

II.3. Types of informed consent

Several classifications of informed consent have been highlighted in the literature. Depending on its basic characteristics, the following have been defined: broad, global, open, legal and meta-consent.

Broad consent is used for one research project only; it cannot be re-adapted or used in other research. (Cheung, 2017)

Global consent has an undefined range of options and mostly respects the autonomy of a research participant. (Mats G Hansson Claus R Bartram, Joyce A Carlson, Gert Helgesson, 2006)

Open consent requires full disclosure of privacy on the part of research participants who, in doing so, should "demonstrate an understanding of the nature of the research and the risks involved prior to enrolment". (Ball *et al.*, 2014)

Legally-transferable consent refers to the right of a research participant to decide what type of data (e.g. genetic sequences, medical records, patient-reported outcomes) to disclose for research purposes. (Cheung, 2017)

Meta-consent allows a research participant to choose what type of consent they wish to provide, what type of data they are willing to provide, and how and when they wish to give their consent. (Budinsne *et al.*, 2017)

II.4 The process itself and the conditions for obtaining informed consent

The ability of informed consent to protect personal autonomy depends on several conditions being met. Three recognised conditions for informed consent in general are reported in the literature:

1. The patient receives adequate information about the proposed medical procedure and understands this information;
2. The patient is competent to deliberate on the consequences of the suggested medical procedure and on this basis is able to decide whether or not to undergo it;
3. In the process of obtaining consent the patient is not coerced, manipulated or unduly influenced

by medical staff or other persons. (Ploug and Holm, 2013)

The steps in the process of obtaining informed consent are:

1. Provision of information: patients and their representatives should be provided with explanations of the nature of the disease or condition, the proposed diagnostic steps and/or treatments, the likelihood of their success, the existence and nature of the anticipated risks and benefits, the existence of the benefits and risks of potential alternative treatments, including the option of no treatment. In achieving this aim, the language used should be as simple, understandable and developmentally appropriate as possible.

2. Assessment of the patient's and/or representative's capacity to understand:

- Assessment of decision-making capacity is an essential step in obtaining consent,
- Often, assessment of decision-making capacity, understanding of the appropriateness of decisions and understanding of medical information take place simultaneously.

3. Verification that the expression of consent is voluntary and that the patient and/or their representative are free to choose between existing medical alternatives without undue influence, coercion or manipulation: this condition recognises that we are all subject to subtle decision-making pressures and that medical decision-making cannot take place in isolation from other concerns and connections. (Katz and Webb, 2016)

II.5 Standards of informed consent expressed by parents/legal representatives

In discussing paediatric decision-making, it is important to distinguish between competence and decision-making capacity. In the US, competence is related to legal status determined by the judiciary and is not determined by clinicians, although the judiciary relies on clinicians. By law, except in specific circumstances, children are not legally competent to authorize medical care for themselves.

Decision-making capacity is the ability to make concrete decisions at specific points in time, which is distinct from competence. It is clinicians who determine children's capacity to make decisions. Children have different capacity to make decisions, depending on their age, the risks and benefits of the decision, their emotional and cognitive maturity, and temporary and permanent limitations in cognitive function (e.g. sedation).

'Informed permission' is used instead of informed 'consent' because 'consent' implies that the patient gives consent within a legal framework. The implication of "informed permission" is that while clinicians almost always honor the parents' decision, the parents' decision is not bounded. Clinicians respect parental decision making because they assume that parents always act in the child's best interest, parents must live with the consequences of that decision, and parental values and goals

often approximate their child's values and goals.

The limits of parental decision-making are given by the 'best interests of the child' standard, which requires parents and doctors to choose decisions from a range of reasonable options. This standard forces clinicians to insist dogmatically on what they believe is best for the child. (Clendenin and Waisel, 2010)

II.6 Factors influencing informed consent in paediatric practice

II.6.1 The influence of cultural and spiritual-religious factors in decision-making

In a multicultural and growing society, providing health care is a difficult task because each service recipient has different life experiences, beliefs, value systems, religions, and notions of health care. Cultural practices and spiritual beliefs are the foundations on which many lives are based, and quality care requires health care providers to be both culturally sensitive and culturally competent (Wiener *et al.*, 2013)

Culture is a collective sense of consciousness with quantifiable and unquantifiable components that can be revealed audibly or silently through history and language. Culture is never static and is typically reinforced by structures, even if these structures are not always palpable and visible, as physical structures are. (Betsch and Böhm, 2016)

Facing the potential loss of one's own child is a catastrophic experience in all cultures (Die Trill and Kovalcik, 1997); however, the literature suggests that cultural influences may further complicate the appropriate integration of paediatric palliative care. A study by (Davies *et al.*, 2008) found that nearly 40% of healthcare providers identified cultural differences as a commonly encountered barrier to appropriate pediatric palliative care.

II.7. Involving children in decision-making and obtaining informed consent

The child-friendly approach to health care, based on the United Nations Convention on the Rights of the Child and endorsed by the Council of Europe, states that children's participation in their own health care and the development of health systems and policies are among the essential elements needed to ensure children's access to health care and optimal health outcomes.

As all European countries have ratified the UN Convention, children's participation in society and health systems is required. Ensuring the participation of young people, especially young children, requires knowledge, self-confidence, imagination and trust on the part of both service providers and their paediatric patients..(Ehrich *et al.*, 2015)

The value of involving the child as an active participant in the care process is invaluable, bringing physical and psychological benefits and enhancing the child's sense of self-determination. Participation

enhances children's cooperation with their carers (Coyne, 2006) and they gain knowledge, skills and responsibility for their care. However, there is little evidence that child patients are actively involved in the decision-making process (Coyne, 2008). Children's ability to give consent, and therefore their ability to be involved in decisions about their care and treatment, is complex and inconsistent. Informed consent is not a static concept and many factors make it confusing and complex. However, assessments of children's competence to give informed consent is variable (Ross, 1997; Rushforth, 1999; Charles-Edwards, 2001; Flatman, 2002). It seems that child patients are considered competent if they agree with health professionals and incompetent if they refuse treatment (Flatman, 2002)

The principle of autonomy is essential when discussing informed consent. Even when young children are involved, choice and decision-making are the reasons for disclosure to children.

The Royal Australian College of Physicians, which oversees Australian paediatric practice, has not developed explicit standards or recommendations regarding information provision, but makes recommendations regarding patient involvement in decision-making processes; believing that the rights of all children and adolescents to be involved in decision-making about their own health must be taken into account. (Hudson, Spriggs and Gillam, 2019)

The American Academy of Pediatrics policy statement on family-centered care is more explicit about children's right to access health information in decision-making; pediatricians should share information with all children and promote their active participation, including children with disabilities, whether or not they are able to participate in managing and directing their own health care. (Eichner *et al.*, 2012)

In its guidance for the 0-18 age group, the UK General Medical Council advises doctors to involve children and young people in the process of informing them about their care, to be honest and open with them, and to give them opportunities to ask and answer questions honestly and to the best of their ability while giving them the respect they would give adult patients. In terms of decision-making, they recommend involving children and young people as much as possible in decisions about their care, even when they are unable to make decisions for themselves. (Hudson, Spriggs and Gillam, 2019)

II.8. Informed consent in the context of the Covid 19 pandemic

The COVID-19 pandemic, with its lack of resources, physical remoteness and urgency, has also raised a number of profound questions in both clinical and research settings about the applicability of informed consent standards; whether or not they should be modified, and if so how this should be done.

COVID-19 treatment often required decisions to be made quickly, and some settings were

overwhelmed with patients needing urgent care, so there was less time than usual to communicate information (McGuire *et al.*, 2020)

Recognizing that the COVID-19 pandemic has raised questions about informed consent or clinical research, the Food and Drug Administration (FDA) and the Office for Human Research Protections (OHRP) have issued statements related to the protection of human subjects in response to COVID-19. These guidance documents focused on the details of electronic informed consent and reiterated that obtaining consent is more than a signature, it is a process. These statements also reinforced the aspirational goals of informed consent that have never been fully achieved. (Rothwell *et al.*, 2021)

II.9 Informed consent in paediatric palliative care

The American Academy of Pediatrics (AAP) has outlined the principles of palliative care that should be followed when caring for children with life-limiting or terminal conditions. These principles include: respect for the dignity of patients and families, access to competent and compassionate palliative care, support for caregivers, better professional and social preparation for palliative care, and continuing to improve pediatric palliative care through research and education. (Harrison *et al.*, 2014)

Parental decision-making is a critical issue during the provision of paediatric and end-of-life palliative care (Chambers, 2003; Weissman, 2004; Liben, Papadatou and Wolfe, 2008; Mack *et al.*, 2011). The decisions parents face are diverse, ranging from deciding whether to issue a do-not-resuscitate or do-not-intubate order, to cease some form of sophisticated life-sustaining care, to limit artificially directed nutrition and hydration, or to request that a child receive a tracheostomy or additional surgery (Patel *et al.*, 2009) up to the decision whether or not to take the child home and provide palliative care at home (Carroll *et al.*, 2012)

Formulating the problem appropriately, communicating information, identifying goals and preferences are difficult enough, but add to this the emotional context in which decision-making takes place and the challenges increase.

The role of parents and the nature of their participation in decision-making for and with their children are unique. Parents' own goals and preferences are not reflected in the decision-making process in the same way as they would be for a person deciding alone. (Fraser, Bluebond-Langner and Ling, 2020). Research has found that parents' attitudes to caring for their seriously ill child are strongly guided by their understanding of their role. This role is defined by two aspects: carer/protector and provider. (Hinds *et al.*, 2009)

III. Communication of diagnosis and prognosis

III.1 Concepts and definitions

Communication is a very important part of medical practice. It is necessary to inform the patient about the disease, treatment, prognosis, course of illness and complications, what to expect in the case of a terminal illness, options and time remaining, helping to remove fears about the unknown and providing information that empowers decision-making (Singh *et al.*, 2015)

In medical practice, communication is a process that enables the establishment and strengthening of a therapeutic relationship which, centred on a process of interaction, seeks to identify, understand and meet the psychological and psychosocial needs of patients and their families.

Communication is a key determinant of patient satisfaction and plays an important role in the quality of services provided by health professionals. (Newell and Jordan, 2015)

Bad news is also defined as any unpleasant information, disagreeable content related to the patient and conveyed to the patient by the caregiver or family, which implies a drastic change in future outlook and/or health prognosis. The content and context of bad news is usually associated with death, serious illness and cancer. Bad news communication occurs in situations that may negatively alter, in part or radically, the future lives of the people involved - patient, family and community.

The way health professionals communicate bad news can generate strong emotional reactions in the people who receive the news, so they will never forget how the communication was made and by whom. In addition, depending on their perception of the experience, they may never forgive the person for the way the bad news was delivered. (Fontes *et al.*, 2017)

III. 2 Brief history of diagnostic disclosure in medical practice

The practice of hiding the truth from patients is old in American medicine and was intended to protect them from the unpleasant consequences of this news. The American Medical Association (AMA) in its Code of Ethics in 1847 stated, "A physician should be far from making gloomy prognostications because a physician should be the messenger of hope and good to the sick." A study done in 1961 showed that 90% of doctors thought it better to withhold cancer diagnoses from adult patients. (Donald Oken, M.D., 1961)

Although expressing adult autonomy has a long history, telling the truth to children was not considered a priority until the 1950s, because until the middle of the last century the causes of child mortality were acute infections and tuberculosis. The incidence of death from cancer increased after advances in medical science such as the advent of antibiotics, vaccines decreased the incidence of death from certain infections. Paediatric specialists had a new problem of talking to their patients about a

disease that "no child has ever been cured of." Lack of experience as well as communication training has left many feeling insecure in the communication process. (Sisk *et al.*, 2016)

The presence of parents is an element that makes communication with child patients different from communication with adult patients, as they often act as moderators in the communication between specialists and children. They are the ones who decide when to communicate with the child, as well as the content of the communication. (Yoshida *et al.*, 2014)

III.3 Communication as an integral part of end-of-life care in paediatrics

Talking about the impending death of a child is a subject that both paediatric professionals and the child's family do not approach lightly. The attitude of "refusing to talk about death" is rooted primarily in emotional factors but also in ethics, many families avoid bad news and any disagreement with medical professionals to validate and maintain their role as protector. (Gaab, Owens and MacLeod, 2013)

Uncertainties in the period at the end of the child's life are multiple, the most important being about the stage of the disease, existing treatment resources, sometimes the absence of information about the diagnosis, its severity and the course of the disease. (Fortier *et al.*, 2013)

Ghidurile existente încurajează profesioniştii din domeniul sănătăţii cum ar fi medicii şi asistenţii medicali să informeze pacienţii şi să discute prognosticul şi perspectivele probabile de viitor. Cu toate acestea, mulţi profesionişti şi pacienţi se luptă pentru a găsi abordarea potrivită pentru aceste discuţii, iar o concentrare primară pe o comunicare deschisă în ceea ce priveşte perspectivele sumbre ale speranţei de viaţă a pacientului implică riscul ca pacientului să îi fie afectate speranţele şi să se simtă copleşit. (Rohde, Söderhamn and Vistad, 2019)

III.4 Guidelines and protocols on breaking bad news

There are several models for delivering bad news that have been proposed and used effectively over the years. These models help to guide and improve the communication of bad news among doctors. Probably the most widely used models are the SPIKES and ABCDE models, but there are others that have been described and used, including the BREAKS protocol and Kaye's 10-step approach.

The common themes in all these models and guidelines are as follows:

1. Preparing for the bad news session
2. Preparing the setting/frame.
3. Exploring patient knowledge, perceptions and expectations
4. Clear and direct communication with the patient.
5. The emotional aspect of the discussion.
6. Summary of the session. (Abdul Hafidz and Zainudin, 2016)

III.5 Revealing the truth from the perspective of health professionals

There are often situations where health professionals, and consequently nurses, are faced with the difficult responsibility of communicating bad news (González-Cabrera *et al.*, 2020)

Communicating bad news can be a challenge for any member of the care team for many reasons, from personal beliefs to feelings of inadequacy or guilt. Some studies suggest that delivering bad news should be a collaborative process and proceed in the same way as delivering good news when all team members are ready to do so (Yazdanparast *et al.*, 2021)

The nurse is an effective communicator with patients and their families and after the doctor delivers the bad news to patients and their relatives, nurses play a key role in supporting and educating them.

Effective communication plays a very important role in the work of nurses, as they intervene after the doctors explain the treatment and its implications to patients, especially when they find that patients find the diagnosis and details of the proposed treatment confusing.

Patients may well not have understood - or misunderstood - what they have been told. Consequently, it often falls to the nurse to reiterate and reinforce this information. (Sonnek and Muilekom, 2013)

III.6 Communication in paediatric palliative care

In recent decades there has been an increased emphasis on providing effective and specialised palliative care for children with life-limiting conditions. Globally, it is estimated that as many as eight million children could benefit from such care each year. (Ekberg *et al.*, 2018)

When a child's cancer disease no longer responds to curative treatment, conversations between parents and professionals become increasingly challenging. Similar conversations have been had at the time of diagnosis confirmation, but now the priorities of care and treatment are changing and so the content of communication will be different. (Lannen *et al.*, 2010)

When a child is nearing the end of life, meetings between the team of caring professionals and the family are recommended to find out what each family's priorities are and to ensure an accurate assessment of all child and family issues (Mathe and Rogozea, 2017)

In palliative care, the delivery of bad news is often associated with discussions of cancer progression, survival time and situations such as active dying, as opposed to curative medicine where there is news of an initial diagnosis or prognosis. Discussions of breaking bad news may need to take

place frequently in an effort to help patients and family members understand aspects of palliative care. (Bumb *et al.*, 2017)

In pediatrics, family-centered communication promotes a dialogue between patients, families and providers and aims to support "more efficient, effective and empathetic pediatric health care (Snaman *et al.*, 2020)

High quality communication is associated with parental peace of mind, feelings of recognition and comfort, and greater trust in the provider. (Sisk *et al.*, 2018)

Clear and compassionate communication is especially critical when discussing prognosis in many advanced stages of cancer care. Not all families ask about their child's prognosis directly, but most want to receive the most detailed information possible about prognosis. (Mack *et al.*, 2006; Blazin *et al.*, 2018)

Understanding prognosis can enable families to review and reframe their short- and long-term priorities (e.g. work, holidays) and treatment decisions, as well as focus on ways to optimise quality time together. (Nyborn *et al.*, 2016). Parents who receive detailed prognostic information report less decision regret than parents who receive less information. (Mack, Cronin and Kang, 2016) Children who participate in discussions around prognosis show less anxiety and feelings of isolation and greater adjustment to illness. (Snaman *et al.*, 2020) In addition, parents who involve their children in discussions about prognosis and impending death generally do not regret doing so. (Kreicbergs *et al.*, 2004; van der Geest *et al.*, 2015) În plus, părinții care își implică copiii în discuții despre prognostic și moarte iminentă, în general, nu regretă că fac acest lucru. (Weaver *et al.*, 2015)

III.7 Communication in palliative care in the context of the Covid 19 pandemic

Infecția cu coronavirus (COVID-19) a avut consecințe importante asupra populației umane la nivel mondial din momentul în care s-a transformat într-o pandemie la începutul anului 2020. (Ekberg *et al.*, 2020)

Care for children with complex and serious conditions had to continue during the pandemic, albeit with adjustments in service delivery. (Spicer, Chamberlain and Papa, 2020; Mehta and Smith, 2020) To reduce the risk of infection, a higher proportion of palliative care consultations during the pandemic were reconfigured into telemedicine. (Spicer, Chamberlain and Papa, 2020; Calton, Abedini and Fratkin, 2020) Guidelines and protocols have been developed to guide clinicians dealing with the rapidly changing pandemic, both within health systems and in society at large. (Bowman *et al.*, 2020) Initially resources about communication during the pandemic focused on communication with and about patients who had COVID-19. Subsequently, additional guidelines were developed for communicating with patients and families who received standard, ongoing care for other conditions during the pandemic. These guidelines provided

suggestions for how clinicians could appropriately communicate with patients about the pandemic in a conversation during a routine clinical encounter. These guidelines were not, however, based on direct observational evidence on communication in palliative care during the COVID-19 pandemic. Furthermore, most guidelines focused on adults rather than paediatric care. (Ekberg *et al.*, 2020)

IV. Personal research

IV 1. Analysis of communication preferences in paediatric palliative care from the perspectives of caregivers of children diagnosed with life-limiting conditions and palliative care specialists - a quantitative study

The study assesses communication preferences in pediatric palliative care from two perspectives: that of caregivers of children diagnosed with life-limiting conditions and that of palliative care specialists.

IV.1.1. Research objectives

The objectives of this research are the following:

- **O1:** To assess communication preferences in pediatric palliative care from 2 perspectives: that of caregivers of children diagnosed with life-limiting conditions and that of palliative care specialists using the Kopra questionnaire;
- **O2:** To assess the ratings of the following 4 specific components of paediatric palliative care communication preferences from the perspective of children's carers and palliative care specialists:
 - o Patient participation and orientation;
 - o Effective and open communication;
 - o Communication for emotional support;
 - o Communication about personal circumstances;
- **O3:** Identify the influence of certain demographic and socio-professional characteristics of caregivers of children with life-limiting conditions (gender, background, age, education, marital status, labour market status, relationship to the child in care and the condition with which the child has been diagnosed) on their communication preferences with paediatric palliative care specialists;
- **O4:** Identify the influence of certain demographic and socio-professional characteristics of

palliative care specialists (gender, education, occupational field, system of palliative care provided in the workplace, and length of time in palliative care) on their communication preferences with caregivers of children with life-limiting conditions;

- **O5:** To identify whether there are significant differences in communication preferences between the 2 categories of respondents, i.e. caregivers of children with life-limiting conditions and palliative care professionals;
- **O6:** To identify the existence of statistically significant positive relationships between the 4 specific components of communication preferences from the perspective of both caregivers of children with life-limiting conditions and palliative care specialists providing care.

IV.1. 2. Research hypotheses

The present research aims to test the validity of 4 general research hypotheses, hypotheses 1 and 2 having, in turn, several specific hypotheses.

General hypothesis 1:

There are significant differences in the communication preferences of caregivers of children with life-limiting conditions with palliative care professionals based on certain demographic and socio-professional characteristics of the caregivers..

Specific hypotheses:

- 1.1. Communication preferences of carers of children with life-limiting conditions with palliative care professionals differ significantly by gender.
- 1.2. Communication preferences of carers of children with life-limiting conditions with palliative care professionals differ significantly according to their backgrounds.
- 1.3. Communication preferences of carers of children with life-limiting conditions with palliative care professionals differ significantly according to their age.
- 1.4. Communication preferences of carers of children with life-limiting conditions with palliative care professionals differ significantly according to their education.
- 1.5. Communication preferences of carers of children with life-limiting conditions with palliative care professionals differ significantly according to their marital status.
- 1.6. Communication preferences of carers of children with life-limiting conditions with palliative care professionals differ significantly according to their employment in the occupational labour market.
- 1.7. Communication preferences of carers of children with life-limiting conditions with palliative care

professionals differ significantly depending on their relationship with the child in care.

- 1.8. Communication preferences of carers of children with life-limiting conditions with palliative care professionals differ significantly according to the diseases with which children in their care have been diagnosed.

General hypothesis 2:

There are significant differences in the communication preferences of palliative care specialists with caregivers of children with life-limiting conditions, depending on certain demographic and socio-professional characteristics of these children.

Specific hypotheses:

- 2.1. Communication preferences of palliative care specialists with caregivers of child patients with life-limiting conditions differ significantly by gender.
- 2.2. Communication preferences of palliative care specialists with caregivers of child patients with life-limiting conditions differ significantly according to their education.
- 2.3. Communication preferences of palliative care specialists with caregivers of child patients with life-limiting conditions differ significantly by occupation.
- 2.4. Communication preferences of palliative care specialists with caregivers of child patients with life-limiting conditions differ significantly according to the palliative care system they provide in the workplace.
- 2.5. Communication preferences of palliative care specialists with caregivers of child patients with life-limiting conditions differ significantly according to their seniority in palliative care.

General hypothesis 3:

There are significant differences between the preferences of palliative care specialists and carers of children with life-limiting conditions in terms of communication between them.

General hypothesis 4:

There are statistically significant positive inter-correlations between different components of communication between palliative care professionals and caregivers of children with life-limiting conditions, from both sides perspective.

IV.1.3. Description of the respondent samples

To assess communication preferences in paediatric palliative care, this research included 2

categories of respondents as follows:

- 1) 212 carers of children diagnosed with life-limiting conditions, i.e. parents, guardians or other relatives;
- 2) 105 palliative care specialists caring for children diagnosed with life-limiting conditions.

The inclusion criterion for caregiver respondents of children with life-limiting illnesses in the study is: being actively involved in the care of a child with life-limiting illness.

The study inclusion criteria of specialist paediatric palliative carer respondents are: working in a specialist paediatric palliative care service, working in a paediatric inpatient service for children with life-limiting illnesses eligible for palliative care, having previously worked in a specialist paediatric palliative care service.

The exclusion criterion for both groups of respondents was refusal to be enrolled in the study.

IV.1.4. Description of the data collection tool

For the assessment of communication preferences in the field of paediatric palliative care, the Kopra questionnaire developed by Farin, Gramm & Kosiol D. was used, translated and applied in Romanian, with the authors' consent. The assessment of communication preferences in the field of paediatric palliative care was done from 2 perspectives: from the point of view of the *caregivers* of children with life-limiting illnesses and from the point of view of the *specialists* in the field of palliative care who care for them, both categories of respondents completing the Kopra questionnaire..

The Kopra questionnaire used consists of 32 closed-ended items on a 5-step Likert scale from 1 to 5, where 1 = *not very important*, 2 = *somehow important*, 3 = *important*, 4 = *very important* and 5 = *extremely important*. Using these items, in addition to the preferences of caregivers and palliative care professionals for communicating with each other, which is the overall factor, consisting of all 32 items, the following 4 sub-factors were measured from the perspective of both categories of respondents:

- *Patient participation and orientation (sub-factor 1) - 11 items: items 1 -> 11;*
- *- Effective and open communication (sub-factor 2) - 10 items: items 12 -> 21;*
- *- Communication for emotional support (sub-factor 3) - 6 items: items 22 -> 27;*
- *- Communication about personal circumstances (sub-factor 4) - 5 items: items 28 -> 32.*

IV.1.5. Data collection, coding and analysis methods

The translated and used Kopra questionnaire was administered from June to November 2021, both in physical format and distributed online using Google Forms in the following institutions providing palliative care to children diagnosed with life-limiting conditions: Hospice Casa Speranței (work points in

Brasov, Făgăraş and Bucharest); Fundația Rafael in Codlea, Hospice Angelus in the Republic of Moldova, Brasov Children's Hospital, "Louis Țurcanu" Children's Emergency Clinical Hospital, Clinic III Pediatrics, Onco-Hematology Department and Fundeni Clinical Institute in Bucharest, Onco-Pediatrics Department. Approvals to conduct the research were obtained from the Ethics Committees or the management of the respective units.

The questionnaire was completed by the following 2 categories of respondents: 212 caregivers of children diagnosed with life-limiting conditions, i.e. parents, guardians or other relatives, and 105 palliative care professionals caring for children diagnosed with life-limiting conditions.

In addition to the responses to the 32 items of the Kopra questionnaire, both categories of respondents were asked for the following personal information:

- Caregivers of children diagnosed with life-limiting conditions were asked to complete information on: gender, background, age, education, marital status, labour market status, relationship to the child in care and the condition with which the child was diagnosed;
- Palliative care professionals caring for children diagnosed with life-limiting conditions who were asked to complete information on: gender, education, occupational fields, system of care provided in the workplace, and length of service in palliative care.

The data obtained were coded with nominal and ordinal values and entered into the S.P.S.S. (Statistical Package for the Social Sciences) database.

IV.1.6 Results, conclusions and discussion

IV.1.6.1. Distribution of respondents caring for children diagnosed with life-limiting conditions

For respondents caring for children diagnosed with life-limiting conditions, the main demographic and socio-professional characteristics analysed were: gender, background, age, education, marital status, labour market status, relationship with the child in care and the condition with which the child was diagnosed.

In the study group it is observed that the majority of respondents are female (79.25%) and only 20.75% are male almost two thirds of the respondents (64.15%) come from urban areas and more than one third of them (35.85%) come from rural areas.

It is also observed that the respondents are aged between 22 and 77 years, the average age is 42.57 years, 47.64% of them are under 40 years old; (52.36%) are over 41 years old.

In terms of the educational level of the respondents caregivers of children with incurable

diseases those with at most secondary education represent 67.97% and those with post-secondary and higher education 32.03%.

Regarding the marital status of the respondents caregivers of children diagnosed in the study group, it is observed that three quarters of them (75.00%) are married persons and one quarter (25.00%) are currently unmarried persons.

Regarding the labour market status of the respondents of caregivers of children diagnosed with life-limiting conditions, it is observed that the majority (81.13%) are employed and 18.86% are inactive in the labour market.

Regarding the relationship with the child in care, it is observed that 92.45% are parents of children diagnosed with life-limiting conditions and 7.55% are guardians or other relatives of the child.

In the study group in terms of the types of conditions with which the children in the care of the respondents were diagnosed, it is observed that 70.76% of the children were diagnosed with non-oncological conditions and 29.24% of the children were diagnosed with oncological conditions.

IV.1.6.2. Distribution of palliative care specialist respondents

In the case of the specialist paediatric palliative care respondents the main demographic and socio-professional characteristics analysed were: gender, education, occupational field, palliative care system in the workplace and length of time in palliative care.

In the studied group, it is observed that the majority of the pediatric palliative care specialist respondents who provide care to children diagnosed with life-limiting conditions (91.43%) are female, while only 8.57% of them are male.

In the study group results in terms of respondents' education, the results show that 82.26% of the respondents have higher education and 17.74% of the respondents have post-secondary education.

In the study group the results regarding the respondents' occupations show that 86.66% of the respondents are specialists working in the medical field (doctors and nurses) and 13.33% are specialists working in the psycho-social field (psychologists, social workers).

In the study group the results show that more than two thirds of the specialist respondents who provide care for children diagnosed with life-limiting conditions (69.53%) provide palliative care in an inpatient system, in hospitals, while 30.47% of them provide palliative care in an outpatient system, in associations, foundations or in patients' homes.

In the studied group, the results in terms of the respondents' seniority in palliative care show that 51.42% have been in palliative care for less than 15 years and 48.58% for more than 15 years.

Sub-factor 1 "Patient participation and orientation"

The results of the study showed that the distribution of the two categories of respondents' ratings of sub-factor 1 is similar. Thus, 70.76% of the respondents caregivers of children and a similar percentage of 71.43% of the respondents specialists in the field of palliative care rate communication between caregivers of children with life-limiting conditions and specialists regarding participation and orientation as important to a great extent and 22.16% of caregivers and 19.04% of specialists respectively rate this component of communication as important to a moderate extent.

Sub-factor 2 "Effective and open communication"

The results of the study showed that the distribution of the two categories of respondents' ratings of sub-factor 2 is similar. Thus, 78.83% of the child caregiver respondents and a slightly higher percentage of 81.90% of the palliative care specialist respondents rate communication between caregivers of children with limiting conditions and life specialists regarding efficiency and openness as important to a great extent and 15.56% of caregivers and 7.61% of specialists respectively rate this component of communication as important to a moderate extent.

Sub-factor 3 "Communication for emotional support"

The results of the study showed that the distribution of the two categories of respondents' ratings of sub-factor 3 is similar. Thus, 51.88% of caregiver respondents and a slightly higher percentage of 59.04% of specialist palliative care respondents rate communication between caregivers of children with life-limiting conditions and professionals regarding emotional support as important to a great extent and 38.21% of caregivers and 26.67% of professionals respectively rate this component of communication as important to a moderate extent.

Sub-factor 4 "Communication about personal circumstances"

The results of the study showed that the distribution of the two categories of respondents' ratings of sub-factor 4 is slightly different. Thus, while most of the caregiver respondents rate communication between caregivers of children with life-limiting conditions and professionals about personal

circumstances as important to a small (40.56%) or moderate (34.91%) extent, most of the professional palliative care respondents rate this component of communication as important to a moderate (39.05%) or large (33.33%) extent.

General factor: communication preferences between palliative care professionals and carers of children with life-limiting conditions, from the perspective of both categories of respondents

The results of the study showed that the distribution of the two categories of respondents' ratings of the general factor is similar. Thus, 61.79% of child caregiver respondents and a slightly higher percentage of 68.58% of palliative care specialist respondents rate the communication of specialists with child patients with life-limiting conditions as important to a great extent and 30.66% of caregivers and 21.90% of specialists respectively rate this communication as important to a moderate extent.

The analysis and interpretation of the data resulted in significant differences in the ratings of caregiver respondents of children with life-limiting conditions by gender.

Thus, it was found that female respondents valued communication with palliative care professionals more highly than male respondents both in terms of the general factor of communication with professionals and in terms of the four specific components of this communication: participation and guidance, effectiveness and openness, emotional support and personal circumstances.

It was also found that rural respondents rated the elements of communication with palliative care professionals related to personal circumstances as more important than urban caregiver respondents.

The results also showed that there are significant differences between caregiver respondents of children diagnosed with life-limiting illnesses who are employed and those who are inactive in the labour market, both in terms of overall factor scores and in terms of scores for 3 of its 4 component sub-factors, namely: patient participation and orientation; effective and open communication; and communication for emotional support. Thus respondents not in employment rate aspects of communication with palliative care specialists higher than employed respondents on the overall factor and the sub-factors: patient participation and orientation; effective and open communication; and communication for emotional support.

It was also found that the communication preferences of caregivers of children with life-limiting conditions with palliative care professionals differed significantly according to the diagnosis with which the children in their care were diagnosed, both in terms of scores on the general factor and in terms of scores on two of its four component sub-factors, namely: communication for emotional support and communication about personal circumstances. Thus caregiver respondents of children with non-oncology diagnoses place a much higher importance on communication with palliative care professionals compared to caregiver respondents of children with oncology diagnoses both in terms of

overall communication and aspects of communication related to emotional support and personal circumstances.

Differentiating criteria of caregiver respondents of children diagnosed with life-limiting illnesses related to age, education, marital status, relationship with the child in care do not significantly influence the ratings of communication with palliative care professionals.

The analysis and interpretation of the data showed significant differences in ratings between the outpatient and inpatient palliative care specialist respondents. Thus, outpatient palliative care specialist respondents rated the communication aspects of the sub-factors patient participation and orientation and effective and open communication as being of higher importance than inpatient palliative care specialist respondents.

Differentiating criteria of specialist palliative care respondents related to gender, education, occupation and length of service significantly influence their communication ratings.

Independent sample t-tests showed that specialist palliative care respondents rated communication with caregivers of child patients with life-limiting conditions regarding personal circumstances as of higher importance compared to caregiver respondents of these children. De asemenea s-a mai constatat:

- The existence of highly statistically significant positive correlations in the communication preferences of caregivers of children with life-limiting conditions with palliative care professionals related to the general factor (communication preferences of caregivers of children with life-limiting conditions with palliative care professionals) and all four specific sub-factors (patient participation and orientation, effective and open communication, communication for emotional support, communication about personal circumstances).
- The existence of highly statistically significant positive correlations in the communication preferences of palliative care specialists with caregivers of children with life-limiting conditions with respect to the general factor (communication preferences of caregivers of children with life-limiting conditions with palliative care specialists) and all four specific sub-factors (patient participation and orientation, effective and open communication, communication for emotional support, communication about personal circumstances).

The results of this study demonstrate that both categories of respondents value communication and that how palliative care professionals communicate with caregivers of children with life-limiting conditions and vice versa influences the therapeutic relationship.

IV. 2. How to communicate the diagnosis of a life-limiting condition - a qualitative study

IV.2.1. Introduction

Good communication is integral to developing meaningful connections between individuals and is an essential aspect of the therapeutic alliance (Kaye *et al.*, 2018)

IV.2.2. Study objectives

Following the experience of daily clinical practice in the Hospice Casa Speranței Brasov Foundation and following the consultation of the literature, the objectives of the study were outlined:

O.1 To highlight how families of children with incurable diseases received information about their child's diagnosis.

O.2 To highlight how health professionals communicate diagnosis, prognosis and treatment options

O.3 Highlighting communication features in paediatric palliative care

IV.2.3 The research question

The research started from a desire to find out how parents of children with life-limiting conditions learned their child's diagnosis from specialist doctors?

IV.2.4. Metodologia de cercetare

A qualitative interview study was conducted between June 2021 and August 2021, for which approval was obtained from the Scientific Research Ethics Committee of Hospice Casa Speranței Brasov and subsequently identified 15 caregivers of child patients under the care of Hospice Casa Speranței Brasov.

IV.2.5. Results and conclusions

All caregivers were female, i.e. mothers of the child patients. At the time of the interview, six of them were employed as carers for a disabled person (their own child) and nine were legally employed in other institutions/firms. The ages of the interview participants ranged from 31 to 45 years.

Five of the children were diagnosed with oncological diseases, one with genetic disease and nine with neurological conditions.

Following analysis and coding of the data collected, three thematic domains were identified, each with a variable number of subdomains:

Domain A *Establishing diagnosis with the following sub-domains:*

Sub-domain A.1 - Time to confirmation of diagnosis - responses showed that this is variable for children with cancer disease and is influenced by the condition. In the case of children with neurological diseases, it is notable that most were diagnosed within a relatively short time of first being reported.

It is noted that even in situations where they are not explicitly told about their child's health, mothers intuit or suspect their child's possible problems.

Subdomain A.2. - Need for second opinion - from the reports of the mothers of these children it was found that most of them needed more than one specialist opinion: either they felt the need for a second opinion or they were referred by the family doctor or specialist doctor who raised the suspicion of a life-limiting condition.

Subdomain A.3. - Stigmatisation emerges from the statements of several mothers interviewed and also reveals the tacit suffering of the parents of children diagnosed with life-limiting conditions, they intuit, often realise themselves the seriousness of the problems but are hurt by the fact that sometimes they do not receive the support they seek from specialists, they are looking for that "possible normality" and acceptance for their children.

Domain B *Diagnostic communication consists of the following subdomains:*

Subdomain B.1 Professionals' attitude - Seven of the professionals who communicated the diagnosis had an inappropriate attitude, which was not agreed by the parents.

Subdomain B.2. Diagnosis communicated briefly, without explanation - this was also not liked by the mothers in the study, who wanted more explanation. However, all mothers stressed that all professionals told the truth.

Subdomain B.3. Nonverbal language foretells bad news - many mothers in the study reported that the doctor's nonverbal language made them realise that something serious was happening to their child before the child started talking.

Sub-domain B.4. Use of medical jargon - It is noted that the use of medical jargon by the specialist is used with ease, often disregarding the parents' lack of medical knowledge.

Subdomain B.5. Place of communication - 9 of the mothers received the news of their child's diagnosis in the doctor's office, 2 in the hallway, 3 in the ward and one in the emergency room.

Domain C - Parents' needs - consists of the following subdomains:

Subdomain C.1. Need for further explanation - Some of the mothers said that they did not understand everything from the beginning, that there were many medical terms, unfamiliar to them and they needed further explanation. Even those who did understand stressed that they wanted further explanations or some said they needed new explanations during the course of their illness.

Sub-domain C.2. Need for respect from professionals - from the responses of the mothers in the study it is clear that they want to be treated with respect, not to be offered stupid explanations and not to be accused.

Sub-domain C. 3. Need for the truth - It is clear that all mothers want the truth about their child's illness, moreover they want as much clear and complete information as possible and they want to be spoken to in a way that makes sense to them.

Subdomain C. 4. The need for palliative care - the mothers interviewed noted important differences between the way of communicating in hospitals and in palliative care. Here they felt that they were not judged and that they would be listened to and get help whenever they needed it.

IV.2.6. Conclusions

The news that a child is suffering from a life-limiting illness is a traumatic experience for parents, only the kindness, tact and empathy of professionals can ease the suffering and help in the fight against the disease

Medical professionals communicate the truth about a child's incurable illness and this is also desired by parents. The day-to-day work of healthcare professionals sets new directions in communication, making it honest and open. (Mathe and Rogozea, 2017)

In most cases it was noted that almost all parents suffered an emotional shock when they received the news of their child's illness and that many took time to come to terms with the situation.

Some professionals communicate empathetically, in a supportive manner and this is greatly appreciated by parents of children with incurable conditions.

In communicating the diagnosis of an incurable disease, medical jargon is often used, terms that are not understood by parents of children with incurable diseases because they have no medical training.

It is also worth noting that many parents feel that the disease is a stigma, are upset that they are treated differently, and feel that their children are somewhat marginalised.

Palliative care services are a real benefit for both children diagnosed with incurable conditions and their carers.

V. Discussion. Original contributions. Limits and future research directions. Dissemination of results. Original contributions

Synthesis contributions:

The present PhD thesis contains summaries of:

- The general context of informed consent in paediatric palliative care.
- The specifics of communication in paediatric palliative care.

Scientific experimental contributions

- Conducting an international multi-centre study (Romania and Republic of Moldova) in paediatric palliative care units, wards and hospital departments where there is a palliative approach to the care of children with incurable conditions on the communication preferences of caregivers of children with incurable conditions and paediatric palliative care professionals.
- To conduct a qualitative study of how healthcare professionals communicated their child's diagnosis of an incurable condition to parents and the impact of this communication.
- **Scientific curricular contributions**Elaboration of scientific research reports within the PhD programme.
- Completion of the PhD thesis
- **The innovation of the PhD thesis**
- Conducting for the first time an assessment of the communication preferences of caregivers of children with incurable conditions and pediatric palliative care professionals.
- Adaptation and application of the Kopra questionnaire in paediatric palliative care services in Romania and the Republic of Moldova

Benefits of research results

- The results of the research demonstrate the scientific value of using the Kopra questionnaire to assess the communication preferences of caregivers of children with incurable conditions and pediatric palliative care professionals.
- Educationally: the development and piloting of an educational curriculum specific to communication in paediatric palliative care and the need to include mandatory communication modules in continuing medical education programmes for healthcare professionals.
- Opening up new horizons of research and clinical practice for nurses in specialised children's palliative care services.

Limitations and future research directions

A limitation of the quantitative research is that the study addressed the primary caregiver of the child with an incurable condition receiving palliative care, which did not allow exploration of the communication preferences of the entire family of these children.

Another limitation was that the communication preferences of caregivers of children with incurable conditions and pediatric palliative care professionals were assessed at a single point in time. These preferences may change due to changes in the children's health or due to certain consequences of treatment.

Another limitation was the context of the COVID 19 pandemic in which the researcher was not allowed access to certain medical facilities.

The main limitation was the non-inclusion of children in the study. Children have the right to be involved in discussions about decisions related to their own health, there are even recommendations and legislative guidelines to this effect. (Mathe and Rogozea, 2022).

Future research directions:

- Investigate and find questionnaires applicable to children receiving palliative care to explore their communication preferences.
- Conduct comparative analyses of palliative care children's communication preferences with those of their caregivers and care professionals.
- To conduct a qualitative study of professional difficulties in communicating a diagnosis of a child's terminal illness..

Dissemination of results

Dissemination and exploitation of results was achieved through:

- Publication of 3 articles and presentation of 4 papers at national conferences.
- The presentation of scientific research papers and the production of scientific research reports included in the training programme of the doctoral school.
- Completion of the doctoral thesis

Nr crt	ISI	Database	Unindexed	Total
1. Articles in journals First author/single author		3		3
2. Conferences - First author/single author			4	4
TOTAL		3	4	7

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