

COMMUNICATING THE DIAGNOSIS OF LIFE – LIMITING ILLNESS OF A CHILD – MOTHER`S PERSPECTIVE

T.C. MATHE^{1,2*} J. VOSIT STELLER³
L. ROGOZEA¹

Abstract: *The aim of this study was to identify how mothers of children with life-threatening illnesses receive and process news of their child's diagnosis. Interviews were conducted to identify categories and themes that characterize how mothers reacted to receiving difficult medical information about their child. The present study was conducted between June 2021 and August 2021. Mothers of 15 children who were patients in the care of Hospice Casa Speranței, Braşov, RO were identified. Five of the children were diagnosed with oncological diseases, nine with neurological diseases, and one with a genetic disease. Qualitative analysis identified three domains: Diagnosis, Communication Style, and Needs of Mothers. Saturation of the data was reached and further identified several themes related to these categories. Results supported that mothers of children with life-threatening illnesses want to know the truth, prefer professionals to be patient, gentle, respectful, and to be supportive throughout the course of the illness.*

Key words: *Communication, diagnosis, life-threatening illnesses, truth, healthcare.*

1. Introduction

The aim of this study was to understand how mothers of children with life-limiting illnesses receive the news of their child's

illness, to identify their feelings and reactions, and to determine how they would want this communication to occur.

Communicating bad news to patients and their families is a complex and

¹ Faculty of Medicine, *Transilvania* University of Braşov

² Hospice Casa Speranței Braşov

³ University of Maryland Baltimore

* Corresponding author: teodora.mathe@hospice.ro

stressful interaction [1]. Professionals must provide relevant medical information and at the same time respond empathetically to the concerns and expressions of the patient and family in order to adapt the information to the needs of each individual [2].

Communicating the bad news to a parent that their child has a lifelong disability or life limiting illness is an unavoidable and challenging task. The bad news signifies a “hopeless feeling” and “threats to well being” and “a loss of choices about the future [3]. Receiving bad news may involve information about diagnosis, prognosis, or treatment failure. This information negatively affects daily routines and future plans. This experience depends on the communicator's understanding of the meaning of life, can lead to reflection and is influenced by previous experiences. It involves emotions resulting from a combination of physiological, psychological, and sociological aspects as well as professional habits [4].

Communicating sad news is a significant part of the clinical decision making of any professional's work, it can become a burden for both the patient and the clinician, and the difficulty of this interaction can affect both [5]. Communication of unfortunate news in pediatrics is exceedingly difficult and can be defined as discussions between professionals and parents about children's serious diagnosis, concerns about their child's severe condition, treatment possibilities or poor prognosis.[6] Honest and precise communication is necessary when discussing the disease and its prognosis. Insufficient training, different expectations, and perceptions of professionals or patients can lead to

dissatisfaction and misunderstandings about clarity and content of communication and skills and empathy [7].

A patient or a family member will have certain preferences about how they receive bad news and these preferences will depend on their own individual characteristics and culture [8]. The way health professionals communicate bad news can generate strong emotional reactions in people who receive the news, so they will never forget how the bad news was shared and by whom. In addition, depending on their perception of the experience, they may never forgive the person for the way the information was delivered [9].

Recommendations encourage health professionals such as doctors and nurses to continuously inform patients of the details of treatment, discuss prognosis, and plan, or address goals of care. Still, many professionals and patients struggle to find the right approach to this discussion and a discussion about limited patient life expectancy overwhelming the parents' need for information and hope [10]. In the past, notions of communicating bad news have not been widely taught but recently several recommendations have been published for this extremely complex and sensitive issue. A popular and agreed protocol with applicability to cancer patients is **SPIKES** published in 2000. The name is an acronym showing the consecutive stages of a discussion. **S** (Setting Up) describes the preparation of the conversation, **P** (Perception) and **I** (Invitation) are the components in which the professional learns the patient's perception of the situation and their willingness to receive the news. **K** (Knowledge) represents the giving of information, followed by

E (Emotions) and finally **S** (Strategy and Summarization) i.e. a final point of view when it is found out if the patient has understood the situation [11].

2. Methodology and Methods

Communicating the diagnosis of a child's life-limiting illness is an extremely sensitive subject and personal experience has shown me that the way it is done is something parents never forget.

The present study was conducted between June 2021 and August 2021. After consulting the literature, we opted to conduct the research using the qualitative method, i.e. interview.

Approval was obtained from the Ethics Commission of Scientific Research of Hospice "Casa Sperantei" Brasov.

15 parents of children patients in the care of Hospice "Casa Sperantei" Brasov were identified.

Their purpose and the content of the study was explained to them and received an information letter and a consent form that they signed. After the audio interviews were conducted, the transcriptions were made verbatim, and the first data were collected.

3. Results

All caregivers were female, i.e. mothers of child patients. At the time of the interview, six of them were employed as caregivers for the disabled person (their child) and nine were legally employed in other institutions/firms.

Demographic data of the participants

Table 1

Gender	Relationship with the patient	Employed as caregivers	Employed in another place
<i>Female</i> n =15	<i>Mother</i> n = 15	n = 6	n = 9

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

Diagnostic categories of respondents' children

Table 2

Oncological diseases	Neurological diseases	Genetic diseases
5	9	1

Following the analysis and coding of the collected data, three domains (thematic areas) were identified, each having a

variable number of subdomains (sub thematic with examples).

Table 3

The results of Qualitative Research Structured in Domains, Themes, and Subthemes with Examples

Domains	Themes	Subthemes with examples
<i>Diagnosis</i>	<i>Time is taken to confirm the disease</i>	Influenced by the type of the disease Children with cancer n =5 "For us it was short, in September 2008 we had a check-up at the neurologist and ophthalmologist,

Domains	Themes	Subthemes with examples
		<p>there they saw problems and recommended CT. We did it the next day, and the third day we had the result".</p> <p>"Everything was long, I went to several doctors, everything took about a year and a half".</p> <p>Children with neurological disease: a short time after the first problems were reported n = 9</p> <p>"The day after I gave birth"</p> <p>The neurologist just examined him. And he told me straight away."</p>
	<i>The need for the second opinion</i>	<p>Most of the mothers asked for a second opinion n = 12</p> <p>"The neurologist examined her and told us that she had microcephaly and sent us to Bucharest. The other doctor confirmed"</p>
	<i>Stigmatization n = 7</i>	<p>In two different situations the use of the term "junk" ("the child is a genetic junk"; "he treated him like a junk")</p> <p>"The doctor told me to do another one, this is not a good child"</p> <p>"At hospice instead, my child is treated as a normal child, nobody considers him different"</p>
<i>Communicating the Diagnosis</i>	<i>The attitude of the professional</i>	<p>Two types of attitudes have been highlighted: appropriate n = 8 and inappropriate n = 7</p> <p>"The doctor didn't dare to tell me but I went and asked".</p> <p>"if you want to go to Bucharest to try a surgery if not the child dies and that's it!"</p> <p>" he was nice, he was sad"</p> <p>"very attentive, seemed to be looking for words and trying to be as gentle as possible"</p>
	<i>Content of the communication</i>	<p>Many of them communicated briefly, they did not give explanations n = 9</p> <p>"Your child has spina bifida and hydrocephalus"</p> <p>"he told me that he has acute lymphoblastic leukaemia, that I will have to take cytostatic treatment, he didn't advise me where to go"</p>
	<i>The use of medical jargon by the specialist is easily noticed</i>	<p>Specialists used terms like: "acute lymphoblastic leukaemia" "cytostatics", "microcephaly" n = 8</p> <p>After parents asked for explanations n = 5 the specialists used terms like:</p> <p>"serious blood disease" "developmental delay"</p> <p>"hole in the back and growing head"</p>
	<i>Doctor's nonverbal language</i>	<p>It is very important for the parents, it often announces the bad news n = 8</p> <p>When he looked at the CT result "I realized something was wrong. I saw that her facial</p>

Domains	Themes	Subthemes with examples
		expression had changed." "On MRI interpretation, there the doctor was nodding his head while looking at the images, he kept looking and nodding his head, I realised that something was wrong.
	<i>The place for communicating the bad news</i>	Doctor's office n = 9 Patients room n = 3 Lobby n = 2 ER n = 1
Mothers' Needs	<i>Need for further explanation</i>	Most of the mothers stated that they needed additional information n = 8 "I honestly didn't understand much" "you always need explanations, in a disease like our daughter's there are always new problems"
	<i>Need for respect and empathy from professionals</i>	All mothers without exception experienced unpleasant feelings when the diagnosis was communicated: horror, fear, anger, etc. "If I were a doctor I would give the parent the confidence that he can fight, that he can carry the burden". "Some look at serious ill children somehow weird, others are nice and want to help, I would like them to be more approachable, to treat everyone nicely".
	<i>The need for truth</i>	All mothers want the truth about their children's diseases. "No matter how painful it is to tell the parent what the child has, don't hesitate" "It's very important to tell parents the truth, the whole truth"
	<i>The need for palliative care</i>	Mothers noted important differences between the way of communication in hospitals and palliative care n = 6 Everyone from hospice knows how to communicate gently, they have the patience to listen and are always calm and encouraging" "Since the boy is in the hospice we are all better, there they talk to us nicely, we have listened too and those people do their best to help us"

4. Discussions

Communication is essential in medical practice. Inappropriate communication can grow the stress and lead to a lack of trust or poor communication [12]. Very good communication is affiliated with

parental peace of soul, feelings of being accepted and comforted, and greater confidence in the professionals [13].

This study has shown once again how important is communication in the medical field. The news is suffering from a life-limiting illness is a traumatic

experience for parents, only the gentleness, tact, and empathy of professionals can alleviate the suffering and help in the fight against the illness. It is very important for mothers to hear the truth, to be spoken in easy and understandable terms and the need for support through the illness has been noted. In most cases, it was noted that almost all mothers suffered an emotional shock on receiving the news of their child's illness and that required time to adjust to the situation. Very often parents need additional information to be given to them after the shock of receiving the news settles. Mothers want to communicate with professionals who are calm, gentle, respectful, and empathetic and need a lot of support. Evidence from several studies suggest that receiving information about the life limiting illness of the child can lead to positive or negative emotions [14, 15]. Some studies have highlighted the importance of certain communication characteristics such as politeness,[14] empathy, sincerity [16, 17], compassion and maintaining hope [17–19].

It is also notable that many mothers feel the disease as a stigma, are disturbed by being treated differently and feel that their children are somewhat marginalised sometimes only because of their physical appearance. Another study finds that children with mucopolysaccharidosis are marginalized because of physical disabilities [20].

A significant difference was noted in terms of communication with mothers of children in palliative care, parents noted an improvement in terms of approaching the patient and family in general and communication in particular. In palliative care service from Hospice Casa Sperantei Brasov, the mothers of these children felt

understood, accepted, and helped in many ways, they felt that the burden of illness and care for the child became easier to deal with.

5. Conclusions

This study shows once again the importance of communication in healthcare. Talking about a child's incurable disease can be uncomfortable, embarrassing, and extremely challenging. However, mothers of children with life-limiting illnesses want to know the truth, they want professionals to be patient, gentle, respectful, and supportive throughout the course of the illness

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