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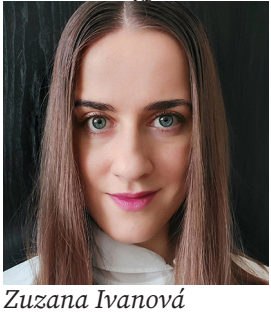

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The needs of a family of a child with terminal disease

Abstract. The aim of the paper is to identify, describe and qualitatively analyse the needs of families with a child with lethal disease. The authors of the article focused on identifying the needs of a family with a child with a lethal disease. They realised qualitative research carried out through interviews with people from helping professions who work with families with a child with lethal disease.

Keywords: lethal disease, family, family needs, special pedagogy.

A child's lethal disease is one of the most challenging periods in a family's life. The family must adapt to the new tasks that the disease brings with it, and everything adapts to the child's needs. However, we are often unaware, and sometimes even the family itself, that the needs of other members must be met. Need is a state of scarcity or excess, which deviates a person from his optimal state. Maslow [4] argues that needs are arranged according to mutual dominance. For a person, the most important needs are at the bottom of the hierarchy, and these are the physiological needs by which a person achieves physical homeostasis. If these needs are not met in a person, the others lose importance, although they may not be met. Other needs include the need for safety, which is as important as physiological needs and is particularly visible in young children, who respond to even the slightest signs of danger, such as parental quarrels. Not only children but also adults need a safe, predictable, and organized world. Third in the hierarchy, the author (Ibi-

dem) mentions the need for love. We understand it by the need for love as such, affection, belonging, and the need to form loving relationships. These are the social needs of the individual. The author does not include in this need a sexual need, which according to him is exclusively a physiological need. Another need is the need for respect. It is a need where a person wants his person to be highly valued, and the basis of this need is his own self-esteem. This need has two dimensions: the desire for strength, for achievement, adequacy, independence and freedom, and the desire for reputation, prestige, recognition, and attention. The last and highest need is the need for self-updating. For human, this need means to become who he wants to be. However, the author (Ibidem) notes that this need will not be achieved by every person in a lifetime. Like Maslow [4], the WHO (cited in Marmot et al., [3]) includes biological needs that are prioritized to be met. Other needs include psychological, social, spiritual, and environmental needs. We also add to this division psychosocial needs, which deal with the psyche of the individual and society, ie especially relationships and their maintenance, because in our conditions the term social refers to the relationship to society, but not to the dimension of relationships, but especially to society as a system.

Research

The aim of our research was to identify the needs of families with a child with lethal disease and to find out whether the needs of the family differ and change in the various stages of the disease described by Kübler-Ross [2]. We chose qualitative research conducted through interviews with workers in helping professions who are in contact with families with a lethal child, and through them we tried to gain a deeper understanding of how they perceive the needs of these families within their profession. Our original intention was to select for research directly families that have a child with lethal disease or families that are already lost. However, after a thorough evaluation, due to the high emotional sensitivity of the topic, we evaluated that families are not interested in participating in research and talking about these painful and still current topics, which was confirmed to us when we addressed 5 families, stating that they were explained how the research was going and no response was received.

For this reason, we decided to involve participants in the research who work with families with a lethal child and participate in meeting their needs. The participants were selected by intentional selection,

which is carried out according to Gavora [1] based on certain relevant features, therefore we set the following conditions for the selection of participants:

- work in the helping profession in palliative care,
- experience with families with a lethal child,
- length of practice in the department min. 1 year.

The research was attended by employees of children's haematology and oncology departments, children's mobile hospice or both, in the case of a priest it was an experience with families of children with lethal disease within his spiritual service.

7 people, 4 women and 3 men were involved in the research. The length of practice in each department ranged from 1.5 years to 43 years, while a priest with 43 years of experience does not work intensively in the department, but it is one of the components of his spiritual service in various places of work.

We used the method of semi-structured interview to obtain data precisely because of its flexibility of adaptability to the participant's statement, which in several cases enabled the acquisition of a larger amount of information. The interview was recorded on a dictaphone, which was then converted into written form. The main questions were compiled based on a study of the literature. As a template for the questions, we used the stages described by Kübler-Ross [2]:

1. stage of shock,
2. stage of denial and negation,
3. stage of anger, feeling of injustice and guilt,
4. stage of depression and sadness,
5. stage of reconciliation and acceptance.

We set 3 areas to which the questions asked by the participants were adapted:

1. Work and experience of the participants within his profession.
2. The greatest perceived need of the family.
3. The needs of the family in the various stages of the child's illness

In the following part, we decided to approach the third, from our point of view, the substantial area, which is the greatest perceived need of the family.

The greatest perceived need of the family

With this question, we wanted to find out whether some needs will be the same despite the variety of professions and services that the family

needs. We have classified the needs into the categories of needs listed by the WHO (cited in Marmot et al., [3]): biological needs, psychological, social, spiritual, and environmental needs. To these needs, we have added, as mentioned above, the category of psychosocial needs.

Doctor

"Well, the family's greatest need is for them to feel like they are doing their best for the child, that they are really involved in the child's whole management and what they're doing, that they can't do more than what they're doing. So, they really feel like I am really doing my best and we do not forget about some important things, we did not miss something, it's really so important for them. Another important thing is that there be a relationship of such trust between doctors and parents, because as soon as the parents begin to doubt or somehow disparage the doctor's decision, then the relationship is so broken and then the relationship is broken by some of the child's management. So, this is very important. And then probably the child's approach to the treatment, about what relationships we establish with the child, because if the child does not cooperate, or has negative attitudes to the doctor, such is his psyche and such his approach to the treatment greatly affects the functioning, so I think that's also very important. "

The participant perceives as the greatest need of the family the need to do everything in her power for the child. We can classify this need into the category of psychological needs. As a need that she perceives as a doctor's relationship with the family, but not directly a need of the family itself, is the need for trust in the doctor and the child's approach and relationship with the doctor.

Nurse

"But the biggest need for them is that they're scared when they go home, huh?" And they need such a sense of security, and we can give it to them when we give them the telephone contacts for us, that they know that they can contact us at any time, and we can travel to them at any time. And this is for them, they always evaluate it so retrospectively that this was a wonderful help, that they knew they had someone to turn to. Then, from the spiritual point of view, if they are believers, they usually have their priests in the place of residence, the clergy to whom they can turn. And then they, the priests, go home to them directly, either giving the last anointing or supporting the family with a conversation or something like that about the

end of life. But not everyone, those priests are so set for this, but most are."

The participant considers the need to have available contact with the hospice care team to be the greatest need of a family with a lethal child. We can classify this need among the need for safety and security, which is also mentioned by Maslow (1943), and we can classify it into the category of psychological needs.

The participant also states that if the family is a believer, there is a need for the presence of a priest, which we could classify as spiritual needs.

Psychologist

"Uhm. There is probably such, I have already mentioned, such a need for such security and safety. As one of those needs is that so that our child, whether they, or the staff who take care of him, can be able to ensure that they suffer as little as possible, that they don't have pain, that they just ... probably most, most perceives to have as such a quality of life, in quotation marks in the sense that if the child is connected to some devices, it may be as comfortable as possible for that child. It is just such a need that he knows we can take care of us and if we do not know, there is someone who can take care of and deal with any health complications that may be. So, I perceive it as one of the biggest, or one of the biggest needs. To give the child such care as possible, and parents are as afraid of it as possible. "

"... to do as much as possible, well ... and after another such need, it may be forgotten, but there is some way to involve siblings, or a wider family, that many times even those siblings might need to explain something, talk , to ask, to be involved in the process and sometimes they are not, sometimes they are, but it is also such a need that the child is in our department, that the child is not in the lethal stage, but when it is simply with us that somehow communicate that you have a sick sibling by that healthy sibling, that this is often a problem for those children we know from the beginning, that there is a prospect that they will be cured. Although I know that the child will be cured, but how ... I have now encountered a case where, as those parents, as if they did not want a sibling to come there to that dying sibling, no, we do not want, we want you remembered him so and so. That, as if, um, such a need to allow all those members to say goodbye to that dying child."

"I think what such needs are, but I probably perceive such a need, such a need, that we know we have safety, a safe place here in the hospital, when something gets complicated, we can come here and they will help us here, that's probably such the strongest, with the fact that I work in a hospital, so probably the siblings and then maybe some such, I don't know, maybe such a need for someone to be around, that's kind of psychosocial help or psychological help. "

The participant perceives as the greatest need of the family the need of the family so that their child does not suffer and the need to provide the best possible care for the child. Both needs can be classified into the need for safety and security and those in the category of psychological needs. The need that the participant perceive as the greatest need in relation to the family is the need for siblings and the extended family to be involved in the context of the child's illness.

Special pedagogue

"What do you need? This is also what you need most to think about. It depends on the family, because sometimes the family needs the loved ones to help them stand, to understand, even the distant family, who may not be able to do it that much. And sometimes this is very good, they can really do it, but again they need, I do not know, maybe they need such support sometimes, some really need that financial support, it's dependent. They are dependent, they fight with such things that they have no money, even though they are trying to improve it now, but also Plamienok is trying to help, but as much as he needs, I think that ... such a closeness of people who are here and they know they are here, that we can call them, and they will try to help us as they know. Because every family is completely different. I do not know a single family that would experience it anyway. Since I met the families of the children I met, they were each different. Every. So, the person needs to look there. But what they need is the feeling that what we need is security for the child that their child is taken care of. To see that care for the child so that he suffers as little as possible and has the greatest possible comfort. This is what they need. That their child, who is ill, is interested in him, in his needs, in that even the time that is before he dies, to be taken care of as best he can. Because the family will give the most that it knows, but as for the health and comfort that the child needs, it cannot do so much. That often other children also need and need to take care of them. So, like all this, he needs help with the whole process. So, the team of people

who works there is very important there, whether they are doctors, nurses, I do not know, social nurse and teachers, hey, because often even those relationships that concern our classmates will go away very much ... "

The answer of the participant shows that she does not strictly perceive one need as the greatest need of the family but mentions up to five needs that she thinks are very important for the family. First, and we can assume that the most important need, the participants state the need for support and understanding from close people. We can include this need in the needs of psychosocial. We can also include in this category the need, which the participants state below, psychological closeness or the presence of another person, which we called as the need for psychosocial support. Financial and material needs are one of the needs that families perceive as insufficient. We can place this need in social needs. We can include in the category of psychological needs the stated need that the child does not suffer and the need to provide the best possible care for the child. However, the participant state in several places of the statement that each family is individual and each experience it differently, so it is very difficult to generalize.

Medical pedagogue

"The need is to have a team of people with you who can turn to him at any time, who will be able to answer his questions and will simply be able to help him in taking care of the child, what else he can do for him and how he can actually help him. "

From the answer of the participant, we can deduce up to two needs, namely the need for accessible contact with the hospice care team and the need that follows it, the need to ensure the best possible care for the child. These two needs, which are closely linked, are safety and security needs that fall within the realm of psychological needs.

Social worker

"I can think of several things that I would call such main things, and that is to be sure that they are not alone in this situation. That when they start something they cannot handle, they pick up the phone, call and someone comes and helps them. I just think it is alpha and omega. Everyone is afraid of the moment, and everyone is afraid that it will not happen dramatically, that it will not be suffocating, that it will not be some cramps and so on. They thought that most of our patients were in oncology, in the ward, treated, so they know what a dramatic situation looks like, and the idea that they should

be left alone without help is, in my opinion, the most frightening of them. It is necessary to be sure that they will not be alone in this situation, that someone will always accompany them, I think it is. And, of course, when it comes to the child, so that it does not have pain, so that it does not suffer. That is where the symptom is nothing out of the ordinary. Pain just destroys everything. You can live without pain and still have some quality of life. It is not possible with pain. So, I think pain regulation and these things. The other needs that arise are just as important, but from my point of view I see this. And when I say this on such a psychosocial level, to constantly feel that someone is listening to them, understanding them and accepting them as they are. That is the basis of every conversation - just believing that what they did is good and right. Basically, it's from every sphere that's the biggest thing. One is from the psychological, one is from the medical, one is from such a social sphere, to have such a feeling of security and to feel that someone will support us in it, or someone will come and help us cope with the situation."

The participant considers the greatest need of the family to be the need for accessible contact with the palliative care team, which is a psychological need, as it is a subset of safety and security needs. In the category of psychological needs, we can also include the stated need of the family so that the child does not suffer. The participant, as another need, he mentions in the question of the greatest perceived need, mentions the family's need to be heard, which is a psychosocial need, as it is a psychological desire of a person to share his problems with another person.

The priest

"So, in the early stages of the disease, every family believes that they will get out of the disease. So, they pray intensely, they lead it into communion, into that unity of prayer, that is, therefore, your prayer, your presence among them, that the pastor, that the priest prayed with us. In retrospect when we had the girl who died here at the age of 15. She was still here on the sacrament of confirmation, she still managed to do it, she was still enjoying it, but the disease had been dragging on for two years soon. Well, there the family, but that is something extraordinary, they were going day-to-day to the Lourdes Cave, the family to pray, they even met there with bishop, he was with them too. They prayed and begged for the girl's healing, and it hosted her state of health in various ways. They also invited me to their home, to pray with her, when they already had her at home,

with her. Well, so, that family judged it that way, now I am jumping a little from your basic question, but this way, the presence of a priest meant a lot to them in support of that prayer, but even after things were clear that it was going. in conclusion, they perceived the prayer and the priest's participation in it very powerfully and were able to reflect on the path of this great suffering themselves. Not only did they accept that it was probably God's will, and so we appreciated it with them, that the Lord God never takes man to catch him as a thief in pears, that he takes man when he reaches ... his personal holiness culminates, to some he adds time to the 90's, to another he soon ... Even her life, that she probably reached the maximum. She was very inwardly open to God even in her time of suffering, and she never grumbled to the girl, and she was still looking forward to catching up with the Burmese. Even a few months before her death, hoping for a miracle, her cousin drove her to Lourdes, up and down. It did not happen, but they also perceived the way again that they were not empty. They were so strengthened in the belief that her, and she ... accepted that time of suffering as preparation for departure or transition to eternity, so that there is no violence against me, no one robs me like a thief, it is my way and the whole family has moved, so it is appreciated that its death has moved all of them closer to God. So, they evaluated the death."

From the answer of the participant, we can deduce two basic needs, which from his point of view the family considers to be the greatest and that is the need for prayer and the need for the presence of a priest. In this sense, the need for prayer is perceived as the need for people or a priest to pray to God for a child, which in this case can be considered a spiritual form of need to do everything in the child's power. Both needs fall into the category of spiritual needs.

From the above statements of the participants, we can see that the most frequently mentioned needs of the family are the needs, which do not concern the parents or siblings themselves, but the needs that are associated with a sick child and caring for him. These needs are, for example, the need for the child not to suffer and to be very closely connected with it, but directly to the need to provide the best possible care for the child. The statements also showed the need for affordable contact with the hospice care team. To these needs concerning the child we can also include the need of the family to do what is possible for the child. These needs relate to ensuring the best possible quality of life

for the child, and this need is present throughout the child's illness. We can say that this need is especially important for parents who are trying to maintain a child's quality of life, but as we said in the chapter on siblings, siblings also need to be drawn into the context of childcare, although we can consider here whether it is about caring for a child, or a form of gaining parental attention. The common denominator of these listed needs is the category of psychological needs, and most of these needs are based on the psychological need for safety and security and the need to care for the other person. Another category of needs that appeared in the participants 'statements are psychosocial needs, in which the participants statements did not agree on one specific need, although these were very similar needs as the need for support and understanding from loved ones or the need for psychosocial support. All these needs are about sharing their problems with other people, giving the family the feeling that they are not alone in the situation and although it is not a psychological need, we could argue that it is a psychosocial transformation of the need for safety and security. She also discovered in the testimonies the spiritual need for the presence of a priest. In both cases, it was the need of believing families, from which we could conclude that this need occurs mainly in religiously based families. As another spiritual need, there was also the need for prayer in the sense of praying other people for the child and the family, and here we can say that it is also about ensuring the best quality of life for the child, only in the spiritual dimension. From the category of social needs, only one need was mentioned, namely the financial-material need, in which it was mentioned that each family is different and can be individual, but in general it is perceived as a need that several participants mention as insufficient for families in later statements. Families must deal with a financial shortage in some cases, as social support systems in this area may be insufficient for the family, especially in terms of income and expenditure. The needs do not differ significantly according to individual professions and include similar needs, except for the statement of a priest who sees spiritual needs as the greatest needs of the family. This may be because in the vocation of the clergyman he tries to meet these needs in families and does not have daily contact with the family, as in other professions. Participants who work in a mobile hospice and meet families in home care perceive the need for affordable contact with the team as the greatest need. This need was also outlined by a psychologist, although in his statement we conceived this need as the need to pro-

vide the best possible care for the child, as families in the haematology and oncology department have 24-hour contact with the palliative care team. From this we can conclude that families with a lethal child who are in the care of a mobile hospice have different needs than families that remain in the ward. Both types of families need the child not to suffer and be provided with the best possible health care, but families in a mobile hospice, who probably also needed to be with the child at home, may fear that the hospice team will not be able to come, or they may be afraid that, although they have been trained in various situations, they will not be able to care at a critical moment, and it is from this fear that the need to have available contact with the hospice care team arises, because it is a matter of providing care for the child. From the above statements, we can conclude that the most important need for the family is to ensure the best possible care for the child or the need that the child does not suffer. We can name these needs as the need to ensure the best possible quality of life for the child. It is interesting that although it is a question of the needs of the family, or in this case especially of the parents, this need is related to the sick child, and it is not a purely need those parents would have. This means that the family is a much more complex system than just the coexistence of family members, between whom there are certain relationships, whether biological or social, but the members are closely linked to each other and, if necessary, mobilize family members care and subordinate their interests to the interests of the child to the extent that the child is subject to their personal needs. The second biggest perceived need was a need for psychosocial support. This need offers the family a kind of social security and at the same time allows them to vent their emotions, while family members know that they will be regulated and directed in some way.

Professional	The greatest perceived need of the family	Categories of needs
Doctor	The need for the child not to suffer	Psychological needs
Nurse	The need to provide the best possible care for the child	Psychological needs
	The need for support and understanding from loved ones	Spiritual needs
Psychologist	The need for the child not to suffer	Psychological needs
	The need to provide the best possible care for the child	Psychological needs

Special pedagogue	The need for support and understanding from loved ones	Psychosocial needs
	The need of psychosocial support	Psychosocial needs
	The need for the child not to suffer	Psychological needs
	The need to provide the best possible care for the child	Psychological needs
Medical pedagogue	The need to provide the best possible care for the child The need for affordable contact with the palliative care team	Psychological needs
Social worker	The need for affordable contact with the palliative care team	Psychological needs
	The need for the child not to suffer	Psychological needs
	Need to be heard	Psychological needs
Priest	The need for the presence of a priest	Spiritual needs
	The need for pray	Spiritual needs

Tab. 1 Overview of the greatest perceived need by profession [5]

Conclusion

The needs of families change in the various stages of reconciliation with death and in the stages of the child's illness, and each stage is characterized by different needs that prevail in the family at that time. Each family is individual and experiences the child's illness differently, so it is necessary to consider the individuality of the family when working with the family.

In the area of professions that work with the family, we would like to recommend, above all, the provision of quality supervision, which should be primarily a matter for the facilities in which employees work.

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