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Family in the situation of a life-threatening diagnosis, child disability

Rodzina w sytuacji diagnozy o zagrożeniu życia, niepełnosprawności dziecka

Abstract

Introduction. A sudden, unexpected diagnosis of a threat to life, or child disability, implies particularly difficult challenges that the entire family system must face, and especially parents who experience difficult parenting.

Aim. The aim of the research was to diagnose the experiences of mothers and fathers who found themselves in a traumatic situation resulting from a diagnosis of a threat to life or child disability.

Methods and materials. The research used the diagnostic survey method, the interview technique and self-developed interview questionnaires with established response categories and open-ended questions, so that respondents could freely express their feelings and emotions. Additionally, as an open-ended question, respondents could express themselves in an essay on the topic: My family. The most characteristic statements were used in the presented article. The parents studied had children with developmental disabilities. The study also used parts of the FACES IV-SOR questionnaire by Olson and Gorall (2006)

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in order to indicate how important the prevailing bonds, family adaptation to a difficult situation, or satisfaction with marital life are in these families.

Results. Research has shown that a sudden diagnosis for the child's condition, which is difficult for the parents, changed the functioning of the entire family system, especially for parents who experience long-term fear in a situation of helplessness and enter a particularly difficult stage of the suffering trajectory. The ability to cope with particularly difficult emotions and stress and to obtain multidisciplinary support affects the quality of relationships and bonds, the family's adaptation to difficult challenges, and especially the conditions for child's development and functioning of the entire family system.

Keywords: family, life threat, disability, child, parental stress, suffering.

Abstrakt

Wprowadzenie. Nagła, nieoczekiwana diagnoza dotycząca zagrożenia życia czy niepełnosprawności dziecka, implikuje szczególnie trudne wyzwania, z którymi musi zmierzyć się cały system rodzinny, a szczególnie rodzice, doświadczający trudnego dla nich rodzicielstwa.

Cel. Celem badań była diagnoza przeżyć matek i ojców, którzy znaleźli się w traumatycznej dla nich sytuacji wynikającej z diagnozy o zagrożeniu życia czy niepełnosprawności własnego dziecka.

Metody i materiały. W badaniach wykorzystano metodę sondażu diagnostycznego, jako technikę zastosowano wywiad oraz kwestionariusze wywiadów w opracowaniu własnym, z ustalonymi kafeteriami odpowiedzi oraz z pytaniami otwartymi, tak aby respondenci swobodnie mogli wypowiadać się na temat swoich odczuć i emocji. Dodatkowo, jako pytanie otwarte, dla respondentów udostępniono możliwość wypowiedzenia się w wypracowaniu na temat „Moja rodzina". Najbardziej charakterystyczne wypowiedzi wykorzystano w zaprezentowanym artykule. Badani rodzice posiadali dzieci o zagrożonym rozwoju. W badaniu wykorzystano również fragmenty kwestionariusza FACES IV Davida H. Olsona i Diane Gorall (2006), celem wskazania, jak ważne w tych rodzinach są istniejące więzi, jak ważna jest adaptacja rodziny do sytuacji trudnej czy satysfakcja z życia małżeńskiego.

Wyniki. Badania wykazały, że nagła, trudna dla rodziców diagnoza dotycząca ich dziecka, zmieniła funkcjonowanie całego systemu rodzinnego, szczególnie rodziców, którzy w sytuacji bezradności doświadczają długoterminowego lęku i wchodzą w szczególnie trudny etap trajektorii cierpienia. Umiejętność radzenia sobie ze szczególnie trudnymi emocjami, stresem, umiejętność uzyskiwania wielospecjalistycznego wsparcia, wpływa na jakość relacji i więzi, na adaptację rodziny do trudnych wyzwań, a szczególnie na warunki rozwoju dziecka i funkcjonowania całego systemu rodzinnego.

Słowa kluczowe: rodzina, zagrożenie życia, niepełnosprawność, dziecko, stres rodzicielski, cierpienie.

Introduction

Difficult parenting, beginning with a diagnosis that is unexpected for parents concerning their child's extremely difficult health situation, causes incredible despair, loneliness and helplessness for parents, who are most often left alone with the problem. It also happens that at this stage they are unwilling or unable to seek help.

A traumatic situation in the family caused by a threat to the child's life or disability is a problem of particular importance for the whole family system, especially for parents experiencing negative experiences of difficult parenthood. In the family's experience of a diagnosis of a life-threatening, disabled child, there is a disruption in the functioning of the entire family system (Barłóg, 2020), "[...] relationships between family members are disrupted, family integration is disrupted" (Szluz, 2019, p. 7). The resulting crisis, the trajectory of suffering completely alters the emotional and social functioning of the family, dismantling the already somewhat stabilised way in which it functions (Sekułowicz, 2010). Every person, the moment they find out that they are going to become a parent, sees, as it were, immediately the perspective of their child's life, their future. The moment of a particularly difficult diagnosis situates the family, as it were, in mourning, introduces a trajectory of suffering, squanders plans and dreams.

Such a trajectory of suffering for the parents can be the cause of their misunderstandings, the break-up of their marriage or their mutual support, and their improvement in their relationship with each other. The sudden diagnosis, difficult for parents, of a life-threatening, disabled child puts them on a trajectory of suffering, can reduce the quality of their lives and often does so, causing a weakening of bonds in the family and difficulties in the adaptation of the mother and father to a situation that is new to them, extremely difficult. It can be the cause of marital misunderstandings, thus reducing the quality of marital life and satisfaction with it, and even leading to the breakdown of the marriage. Sometimes, it also further integrates parents and the whole family system, leading to mutual support, improvement in mutual relations, and responsibility for decisions concerning the future of their child (Pawlikowska, Maciejewska, 2018). The level of parental stress depends on the severity and form of the child's developmental disorder, and the threat to the child's life, health, and development (Kossewska, Wojciechowska, 2017). Parents, despite many difficulties, want to be partners in treatment decisions or diagnostic-therapeutic, supportive-rehabilitation interactions. Mutual partner interaction, empathy, and professional knowledge of professionals can be the best way for parents to accept difficulties and even celebrate their child’s successes in the future (Barłóg, 2019).

Family in anticipation of difficult parenthood

Nowadays, a family with a child’s life-threatening, disabling condition is viewed systemically. According to general systems theory, the family is a particular system of many connections and dependencies. Changes within one element of the system cause changes within the whole family system. Systems theory was introduced by the biologist Ludwig von Bertalanffy in the 1930s, also with the family viewed systemically. What is important here is to describe the processes in question, and the dependencies that occur, and not just to formulate the questions “If” and “why”? The family – especially the one with a child with a threat to health, life, or disability – is also a collection of elements, and subsystems that are in mutual relations with each other (Barłóg, 2020). Contemporary literature recognises the dynamic interrelationships that take place in the family system, especially when the family has to adapt to a new, suddenly created, difficult situation. The systemic view of the family proposed by Andrzej Twardowski exposes the network of connections and interactions between family members, which is characteristic of ecological theories. The ecological approach views the family as a set of interacting individuals who focus on certain norms, values, and communication (Twardowski, 2012).

The implementation of the parenting role is usually directed towards the well-being of the child, as a process it is a sequence of actions for the child’s health, safety and development, meeting the child’s needs. Parenting as motherhood and fatherhood constitute a dynamic process of becoming, of stepping into the role (Kwak, 2008). As contemporary research demonstrates, already prenatal expectations of women and men are filled with joy and enthusiasm, but at the same time with uncertainty and anxiety due to the ignorance of the child’s future (Cacace, Cantelmi, 2013). Most parents make an emotional connection already with their prenatal child. Such imaginings have a positive impact on the emotions, and feelings that are linked to the expectation of the birth of their child (Barłóg, 2020). The very early contact of the mother with the child in her mind already causes an awareness, a sense of the child’s presence, a mutual attachment, an emotional fear, and hope. Fathers – like mothers – also co-sensitise the situation of their child’s arrival in the world, the security of its mother, and the support (Brizendine, 2006). Already in the early stages of the child’s life the bond, the whole communication between mother and child occurs as a two-way process through the mother’s physiological system.

The trajectory of suffering in difficult parenting

The scientific literature draws attention to the interdisciplinary view of human suffering. In general, it can be assumed that suffering is a negative response in the emotional-feeling sphere produced in the higher nerve centres, caused by pain or other situations related to the loss of relatives, which may be accompanied by frustration, depression, stress or anxiety. It can cause despair and hope, light and darkness, it can be destruction or purification, and it can transform and become a *katharsis* (Ravasi, 2004). Concerning parents in the situation of a diagnosis of a life-threatening, disabled child, one can speak of a trajectory of suffering. The precursors here are Barney G. Glaser and Anselm L. Strauss, who developed the concept of the trajectory of dying – "death trajectory" (Strauss, 1989). According to Elżbieta Zakrzewska-Manterys (1995), the basis of the analyses here was the so-called "change of statuses." Researchers of the issue list many dimensions, such as desired – undesired change, reversible – irreversible, protective or not, the person makes the change voluntarily or is forced by circumstances, etc. In contrast, about a family experiencing a difficult diagnosis of a child and perceiving a life-threatening condition or disability, there is a disordered, chaotic phenomenon of parents' abandonment of intentional action and being pushed, as it were, by sudden, unexpected events, which consequently lead to reactivity in all forms of activity. Parents who, in the first stages, enter the omnipresent chaos, experience helplessness and sadness, which successively worsen, hence their behaviour and activity become extremely emotional and chaotic. Their suffering is caused by their inability to free themselves from a situation that is too difficult for them. Unfortunately, this process is progressive (Barłóg, 2015) and parents experience more and more intense and painful suffering for them.

Stages of the trajectory of suffering, a model of the course of trajectory processes was proposed by Franz Schütze (1997). On the Polish ground, the successive phases of increasing trajectory potential are described by E. Zakrzewska-Manterys (1995):

- Accumulation of trajectory material. The trajectory process does not appear suddenly. It increases gradually. The individual himself brings about the growth of the trajectory by rejecting or not paying attention to the signals that appear. This leads to a lack of resources with which the person experiencing the trajectory can cope with it.
- Crossing the boundary between intentional and conditioned mental states. The person feels subjected to external forces and is unable to activate familiar strategies of action.
- A new, unstable equilibrium of everyday life occurs. The person creates a new relative equilibrium concerning everyday matters. The effort put into this situ-

ation takes all the energy out of the individual, causing fatigue, breakdown, a sense of powerlessness in the face of the trajectory, lack of self-confidence.

- A breakdown in orientation towards oneself. The individual at this stage doubts the possibility of returning to the state before the trajectory. There is a complete breakdown, the peak of the crisis so to speak, and the person ceases to cope even with everyday life.
- This stage is followed by attempts to rationalise the trajectory and come to terms with it. A complete breakdown causes a shock, the broken person, affected by the trajectory, notices that something important has happened in his/her life, with far-reaching consequences. He or she has to define the system of action so far. An attempt is made to describe the nature of the suffering, to explain the reasons for the suffering, the reasons for the normalisation and the unjust fate. The question is asked "Why all this suffering?" and "Why does it last?" as well as "Why did it happen to her/him?". This situation definition links to the trajectory process's impact on the course of her/his life going forward.
- Practical work on the trajectory or escape from the trajectory. By adopting a new life pattern, the person begins to carry out actions towards controlling the dynamics of the trajectory or escaping from the process. In this situation, the person can choose:
  - escaping from the trajectory, which is usually not an escape, the individual continues to stay with it,
  - systematically sorting out the life situation, which allows the person to live with the trajectory when the effects of the trajectory cannot be removed,
  - making an effort to remove the trajectory potential by completely reorganising the life situation.

The literature identifies three levels of transformation of parental distress in a trajectory situation into other problem areas:

1. The quasi-metaphysical level – is a continuous, repetitive breakdown that is full of expectations, leading to a lowering of trust in the world as a whole.
2. Interactional level – is the stage of "closing in" of the parents, distancing themselves in their relationships with other people, in extreme cases even to the rejection of help, with the attitude that even loved ones cannot understand them, their position, their experiences and experiences, their state of breakdown, the trajectory of suffering they feel. This inhibition or lack of interaction can eventually result in a lack of interaction initiatives (Schutze, 1997).
3. The level of identity transformation - this is the third stage of the lack of release from parental suffering, which leads further down the line to transformation into further problem areas. It is a holistic process of parental distress

> that is combined with increasing anxiety, which consequently disrupts social interactions as well as causes alienation and may eventually lead to identity disruption (Schutze, 1997).

The parent of a child with endangered life, and health, at risk of disability, is constantly exposed to confronting problems in a situation of anxiety and uncertainty about the child's future. Most often the mother experiences fear of further, unpredictable events, about the child's present and future, and about how her family will function in this situation (Kucharczyk, 2011).

Methodology of own research

Parents experiencing a painful diagnosis of a threat to their child's life, health, or disability experience many traumas. Recognising this situation to try to secure for them not only the diagnosis that is so externally expected but also professional support, seems obvious. It should also be said that there are dynamically positive developments in this area, especially about various forms of help and support. For parents, however, this is always an individual traumatic experience, which often exceeds their capacity to adapt to the new, unexpected situation.

The aim of this study was to identify the experiences of mothers and fathers who suddenly find themselves in a traumatic situation for them, resulting from a diagnosis of a threat to their child's life, health or disability. The research used a diagnostic survey method with elements of a qualitative method; interview, narrative interview and interview questionnaires with questions with suggested answer cafeterias, as well as open-ended questions and an essay on the topic "My family" were adopted as the technique for the research. The research was conducted in 2024 with a group of 30 parents of children at risk of development in the Podkarpackie Voivodeship. The following research questions were adopted:

- What are the most common stages of the parents' suffering trajectory?
- How is the process of exit from the suffering trajectory of the parents under study?
- What is the severity of the symptoms of the "burnout syndrome" in the parents under study?
- How is the adaptation of the parents to the new situation caused by a diagnosis of their child that is difficult for them?
- What is the communication between the parents?
- What is the level of satisfaction with the parents' marriage?
- Is support perceived by the parents surveyed as a determinant of the trajectory of suffering?

Parents in a trajectory of suffering – results of own research

In the study of the trajectory of parental suffering, it should be assumed that there is a highly individualised trajectory of parental suffering. Each individual experiences a characteristic intensity of negative emotions, experiences and anxiety. Nor does everyone go through all its stages. The research confirms that the parents' reaction to their child's difficult diagnosis was accompanied by negative emotions and behaviours, such as disbelief and shock – 96.6% among mothers, 50.0% among fathers, and breakdown (50.0% mothers and 33.3% among fathers). A significant percentage of parents made an effort to seek accurate information and professional, specialised help – 53.3% of mothers and 50.0% of fathers. Parents were accompanied by negative emotions:

- in mothers: anger – 93.3%, resentment towards the whole world – 100.0%, fear and doubt – 36.6%,
- in fathers: anger – 80.0%, resentment towards the whole world – 70.0%, fear and doubt – 36.6%, and even a sense of relief that it is finally known what is wrong with the child – 16.6%.

The research revealed that among the most common stages of trajectory, parents indicated:

- the gradual accumulation of trajectory material (96.6%),
- followed by the sudden crossing of the boundary of making the trajectory potential (87.5%),
- attempts to rationalise the trajectory and cope with everyday life – 72.5%,
- attempts to develop unstable equilibrium and cope with everyday life situations – 85.0%,
- destabilisation of unstable equilibrium and coping with everyday life – 52.2%,
- breakdown of the organisation of daily life and orientation towards oneself – 50.0%,
- practical work on the trajectory and gaining control over it and breaking free from its bonds – 50.0%.

From the parents, it was possible to hear:

> My reaction to the diagnosis was calm, which is not to say that we are not suffering as parents.

> Our daughter was born perfectly healthy, we didn't even realise that after two years of her life, everything could change like that, it took us very much by surprise.

> We blamed ourselves that it was our fault.

> The diagnosis itself was already very difficult, it seemed that it was untrue and that what was happening to the child was temporary, that after consultation with specialists, it would pass by itself.

In the literature, there is a possibility to read that the process of leaving this difficult trajectory can take place in three ways: escaping from the trajectory and not accepting the situation, "getting used to" the trajectory and integrating it into the life situation, elimination of the trajectory potential by completely reorganising the life situation and using the trajectory to strengthen one's personal life experience (Zakrzewska-Manterys, 1995; Górecki, 2007).

When asked about the process of coming out of this difficult suffering trajectory, the parents surveyed admitted that there was a systematic elimination of the trajectory potential (72.5%), and a familiarisation with the trajectory (27.5%). Parents surveyed did not indicate a process of escape from the trajectory. Parents acknowledge that they perceive a sudden accumulation of the suffering trajectory – 100.0% of parents surveyed, with simultaneous attempts to rationalise the suffering trajectory and come to terms with it – 85.5%.

The good biopsychological state of parents, especially the mother, is a prerequisite for the proper fulfilment of the parental role. It is the mothers who experience many burdens resulting from illness, disability and threats to their child's life. The lack of rest, the long-term burden of caring for a child, and the lack of help from others can lead to mental fatigue in mothers as well as the risk of a complex syndrome of "burnout" (Karwowska, 2007).

The study confirmed that there were no mothers in the study group who had a high degree of burnout syndrome. The mothers surveyed described their fatigue as very low and low (89.0%):

> I make no secret of the fact that I feel weak as if I am experiencing some kind of impotence, a lack of strength, a feeling that nothing good has happened to me in life, only suffering and the needs of a sick child, but I never stop believing in my child.

> There are also days when I need to cry, I am at the stage of accepting this situation.

According to the parents surveyed, the level of adaptation to a new situation that is difficult for them is good. This is stated by 64.0% of mothers and 62.5% of fathers. They rank their child's problems and needs among the most painful experiences (93.3%).

What is important is the intra-family communication, the effectiveness of the information communicated, and the degree of control in relation to the attention of the one receiving the information (Adler, Rosenfeld, & Proctor, 2011). For a family in a trajectory situation, the bonds within the family, its adaptation to the new, difficult situation, and especially the level of communication within the family are important (Margasinski, 2015).

The parents surveyed acknowledge that the family has become even more integrated with this new, difficult situation (43.7%) and that communication within the family is often limited to communicating important information (30.2%), while more than thirty per cent indicate difficulties in communication within the family (35.0%). All respondents at the same time state that on important issues concerning their child's future, they can discuss problems calmly so that the child's needs come first (100.0%).

Satisfaction is the spouses' sense of psychological well-being in marriage. A successful marriage is a source of happiness for the spouses, a sense of satisfaction of the need to be accepted, but also to have a close person, to understand their needs (Tatala, Mach, 2014). It is a subjective, individual feeling with regard to expectations and their fulfilment on the part of the spouse. From the parents' statements, only 15.0% of the surveyed parents declare that they evaluate satisfaction with family life at a sufficient level, the remaining respondents highly value marital life and satisfaction, they evaluate satisfaction with marital life at a good level – 55.0%, and even very good – 30.0%. The parents surveyed emphasised that, despite very serious problems resulting from the threat to life, and the child's disability, they feel fulfilled and satisfied with their marriage, with their spouse (83.3%), while the others admit that recent events make it difficult for them to assess satisfaction with marital life. As difficulties, they point to difficulties in adapting the family to new challenges and quarrels within the family (57.0%), but also difficulties in mutual communication (43.0%).

Another study of mothers of children with ASD in 2020 found that these mothers present varying levels of satisfaction with family life, with moderate levels predominating, with few indications of high levels and low levels. This may mean that this kind of opinion is caused by a lack of hope for the child's recovery, the overlapping of various difficulties related to the child's care, anxiety about the child's further future, but also by burnout, resulting in a lower sense of satisfaction with family life (Barłóg, 2020).

It is worth mentioning that despite many difficulties, a significant percentage of parents are fully satisfied with their role as mother and father, i.e., the role of motherhood and fatherhood. The parents surveyed were asked to indicate the people from whom they expect help and support. Thus, all respondents, both mothers and fathers, admit that they expect help and support from their spouse (100.0%), followed by professionals, mainly doctors and nurses (50.0%). It is worrying that the parents surveyed indicate a great deal of loneliness in this respect, although there have been many positive changes in support for such parents in recent years. According to mothers, spouse support was rated at 16.6%, while medical services were rated at 45.0%. According to 83.3% of fathers, there is support from the spouse.

Conclusion

As soon as the parents, but also the whole family, receive information in the form of an initial specialised diagnosis, life changes. Sometimes this diagnosis, which is difficult for them, about their child's health situation forces parents to completely reorganise their lives. As confirmed by the results of the research, in the situation of a sudden, difficult for parents diagnosed with their child's health condition or disability, parents are accompanied by many negative emotions, such as shock or even disbelief, difficulties in accepting such news, anger, rebellion, resentment towards everyone and the whole world. In the case of mothers, negative emotions are predominant, experiences caused by a very difficult diagnosis for them concerning their child.

At the same time, both mothers and fathers admit that the problems and needs of their children are the most painful for them. Simultaneously, the respondents acknowledge that, despite difficulties in mutual relations, and adaptation difficulties in issues concerning their child, there is mutual responsibility and understanding, as the needs of the child, his or her health, are most important.

Similar research among parents of children with ASD (Barłóg, 2020) led to similar results and conclusions from the studies. Parents – both mothers and fathers of children with ASD – mostly assess their own families as functioning properly, and have a sense of mutual closeness, while revealing significantly greater difficulties in adapting to change, to new tasks, and the challenges posed by the mini situation. In the opinion of mothers of children with ASD, good family communication influences the better functioning of the family system, and the fulfilment of the mother's role in motherhood, which is difficult for her. Mothers and fathers of children with ASD who feel isolated rate the family's readiness for change at a lower level. According to fathers, difficulties related to making sudden changes are prevalent in families with a child with ASD. As help and support increased, fathers rated the family situation higher for its integrity and readiness to overcome difficulties. Similarly, mothers became involved in their child's diagnostic and therapeutic process.

As one mother states:

> I feel the whole family blames me, even my husband. We don't go anywhere, there is no time for each other or the marriage. We devote our whole life to the child, to save him, to keep him alive, to keep him from being disabled because I don't

> know what to do with him if he has a seizure.
>
> From now on, how the child is managed, cared for, treated and rehabilitated will depend entirely on the parents' behaviour, and their determination to cure the child or to accept him or her with dignity as the child is. Often parents seek help and support from a wide range of institutions and associations, online forums and other places.

Research has shown the difficult trajectory of parental distress, which is multistage and includes all stages of parents' coming to terms with the threat to their child's health or disability. The question can then be posed: is the modern family with a child with a life-threatening, developmentally compromised, disability in a supportive or isolating situation?

Such a family often avoids other people and isolates itself when it most needs support. It is also sometimes the case that those close to them also avoid such contact, often not knowing how to behave. Such a family often does not allow itself to be helped, feeling rejected, so to speak, and at the same time rejects the much-needed help and support from those close to it (Ohme, 2009).

The literature presents this type of family as a closed family.

Closed family

- physically and mentally burdened,
- alienated and lonely,
- socially rejected, so to speak,
- has no opportunity to learn from other families,
- does not have access to the latest knowledge,
- feels inferior,
- the child's social contacts are limited,
- lack of confrontation with the reactions of others (Ohme, 2009, p. 89).

Open family

- support from others eases the burden,
- can compare how other families cope, learn from them,
- can benefit from the exchange of knowledge, the latest treatment methods,
- feels that it is a different family, but not inferior,
- knows that they can extend the knowledge of others,
- feels needed and important in the community, supports other families,
- the child has the chance to interact with others.

At the same time, it is necessary to propose the inclusion of the family in the process of early childhood development support, moving away from activities focused only directly on the child, to activities focused on the family, and on cooperation with the family. This is the new paradigm of early childhood development support developed by Andrzej Twardowski (2012).

In this paradigm, a special role is attributed to the family and the empowerment of parents as the most important actors in the process of supporting the child's development. An important role is attributed to both enriching parental competence and optimising parents' positive attitudes towards their child's support activities. In the empowerment paradigm, it is proposed both to create opportunities to exercise and improve already existing potentials inherent in the family and to develop new competencies in this area. The intervention proposes to focus on identifying positive qualities and resources within the family to use them to strengthen the child's functioning. The new paradigm also proposes to focus on the child's resources, capacities and positive social influences. Finally, it is a paradigm that emphasises the special role of the family, i.e., family-centred, with professionals as representatives of families and their advocates who respond to their needs (Twardowski, 2012). Individual family characteristics may prevent families from opening up to help and support.

Parents experiencing many traumas, mainly negative ones, due to the very difficult early diagnosis of their child, also when confronted with new challenges they have to overcome, in fear for their child's future, with a sense of loneliness, and uncertainty must receive professional systemic specialist support for both the child and the family. This kind of help for the family system is necessary and expected as early as possible, both from help and support institutions, professionals and close family (Barłóg, 2020).

Today's parents are very keen to "fight" for their child, for their child's health, for their child's development, for their child's future. Therefore, they expect support for their actions, specialised professionalism, positive parenting programmes, and the help they most expect. Despite increasing access to specialists and support institutions, special, peer support, and help are still expected by mothers and fathers in the situation of a sudden, difficult for their diagnosis of a threat to the life or disability of their child. Here, an important role should be attributed to support groups and whole systems of local, community-based support, especially if the expected help is systematic and effective for both the child and its parents.

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