

ORIGINAL PAPER**LIVED EXPERIENCE OF PARENTS OF CHILDREN WITH LIFE-LIMITING AND LIFE-THREATENING DISEASE****Radka Bužgová, Andrea Páleníková***Department of Nursing and Midwifery, Faculty of Medicine, University of Ostrava, Czech Republic***Received January 9, 2015**
Accepted February 11, 2015**Abstract**

Aim: The aim of the research was to identify and describe the problems and experiences of family members caring for children with life-threatening or life-limiting diseases from diagnosis to the eventual death of the child. *Design:* A qualitative study using grounded theory method. *Methods:* The sample consisted of eight family members with experience of direct care of children with life-limiting or life-threatening disease. For data collection a technique of non-standardized interview was used. *Results:* Based on data analysis, four main categories and subcategories were defined: 1. onset of the disease (diagnosis, prognosis and awareness), 2. therapeutical phase (demands of care, the impact of disease and treatment on the family), 3. the acceptance of life with disease (feelings and emotions, coming to terms with disease) and 4. dying and death (dignified dying, the period after death). *Conclusion:* Serious disease in a child is a difficult life situation for parents, associated with changes in their personal and family life. Carers need psychosocial support, especially in the form of advice, and require the exercise of empathy and open communication.

Key words: palliative care, child, family, dying, support, dignity.

Introduction

Pediatric patients with life-limiting and life-threatening diseases constitute a very heterogeneous group of patients. Life-limiting disease in children is defined as a disease which habitually results in premature death. Life-threatening disease is a disease with high probability of premature death due to the severity of the illness, but also the chance of long-term survival into adulthood (Craig et al., 2007, p. 2). These children may be granted some form of palliative care. Palliative care for children is the compact active care of a child's body, mind and spirit, and also includes providing support to the family of the child. It starts as soon as diagnosis is determined and continues regardless of whether the child receives or does not receive treatment in connection with the disease. As with adults, care providers must assess, evaluate and mitigate the physical, psychological and social suffering of the child (WHO Definition of Palliative Care, 2013).

Support for the family should also be granted in the period after the death of the child, thus in the period of mourning.

The development of palliative care in pediatrics still lags behind the development of palliative care for adults. Lack of scientific evidence, outdated concepts and distrust of professionals and amateurs in palliative care, ethical and legal issues, fragmentation of care, limited financial resources, lack of erudition and specialists in palliative care, inadequate assessment and management of symptoms, blind persistence with efforts to cure child patients, and other obstacles, slow down this development and hamper the provision of optimal palliative care to children (Davies et al., 2008, p. 282; Monterosso, De Graves, 2005, p. 275–276).

The approximate number of children that could benefit from palliative care is estimated at seven million annually (Knapp et al., 2011, p. 361). All available studies have shown, that the largest number of deaths occur during the first year of life. In most cases this is due to congenital or chromosomal defects or deformity, and, after the first year, diseases of the nervous system, circulatory system, or tumors. The prevalence of life-limiting illness requiring palliative care is 10–16 : 10,000 children in the total number of

Corresponding author: Radka Bužgová, Department of Nursing and Midwifery, Faculty of Medicine, University of Ostrava, Syllabova 19, Ostrava, Czech Republic, email: radka.buzgova@osu.cz

children aged 0–19 years. 30% of these are neoplastic diseases and the remaining 70% includes combined defects, predominantly neurodegenerative, metabolic and genetic (Huijjer et al., 2009, p. 10–15). In the Czech Republic statistics are only available regarding child deaths. In 2012, 2.6 children per 1 000 live births died during the first year of life. At the age of 1–19 years 19.4 children per 100,000 children died between these ages from other than external causes (deceased 2012).

It is essential that palliative care in children be a unified, well-coordinated service that is available to families, and that it provide support and information in a way that allows them to choose the point of care provision, utilization of available social services, and place of death (Chambers et al., 2009, p. 7). According to the recommended standards for palliative care for children in Europe (Craig et al., 2007, p. 4), the team of carers must have the ability to recognize the individuality of each child and their family and respect their values. Part of the team's work is to support the wishes and desires of the child and the family, as long as the child and caregivers are not exposed to harm.

The most vulnerable group in pediatric palliative care are the parents. Parents, as the legal representatives of the child, often bear a heavy responsibility for personal and nursing care. Disease raises not only social but also ethical issues when the rights of the child, their wishes and participation in decision-making are often not respected (Huijjer et al., 2009, p. 19–20; Chambers et al., 2009, p. 7–8). Monterosso and De Graves (2005, p. 275–276) states that the parents may experience difficulty with unwillingness or inability to switch from curative care to palliative care. They are forced to make very serious decisions in a situation where they have to choose between curative interventions or procedures to ensure physical and mental well-being, which are mutually exclusive. Hill and Coyne (2012, p. 278) found that parents face many battles from the moment their child is diagnosed with a life-limiting disease. Therefore, families with a dying child present a very special challenge. However, as yet the Czech Republic completely lacks a conceptual health policy in the area of the care of incurable and terminally ill children (Student et al., 2004, p. 101–102).

Aim

The aim of the research was to identify and describe the problems and experiences of family members caring for children with life-threatening or life-limiting diseases ranging from diagnosis to the eventual death of the child.

Methods

Design

Due to the sensitivity of the chosen topic, the research was conducted by qualitative method using grounded theory method.

Sample

The research sample consisted of eight family members with experience of direct care of children with life-limiting or life-threatening diseases. They included six parents, one sibling and one grandparent, and consisted of seven women and one man aged between 32–60 years. Six participants were married, one was widowed and another divorced. Five respondents had a university degree and three had completed secondary education. Further characteristics of research participants remain intentionally unstated in order to preserve their anonymity. The sick children consisted of four boys and four girls. At the time of the interview four children were in care and four children were deceased. Of these, three died at home and the fourth in hospital in the ICU. The period of care lasted from a few hours (about 8 hours) to several years (about 9 years). Five children had at least one sibling. The age of the children ranged from one month to 16 years. Two children had a cancer, the others had non-cancer diagnoses. Statements are identified by the names of the respondents, children and siblings, which have been changed to preserve their anonymity.

Data collection

For data collection the technique of non-standardized interview was used. Participants were asked a basic question: “*What is your experience of the care of your seriously ill child?*” The researcher asked further questions in response to the information volunteered. Interviews were conducted in health facilities ($n = 3$), in the working environment of the participants ($n = 2$), and in their home environment ($n = 3$). Interviews were recorded by dictaphone. They ranged from 35 to 210 minutes in length.

Data analysis

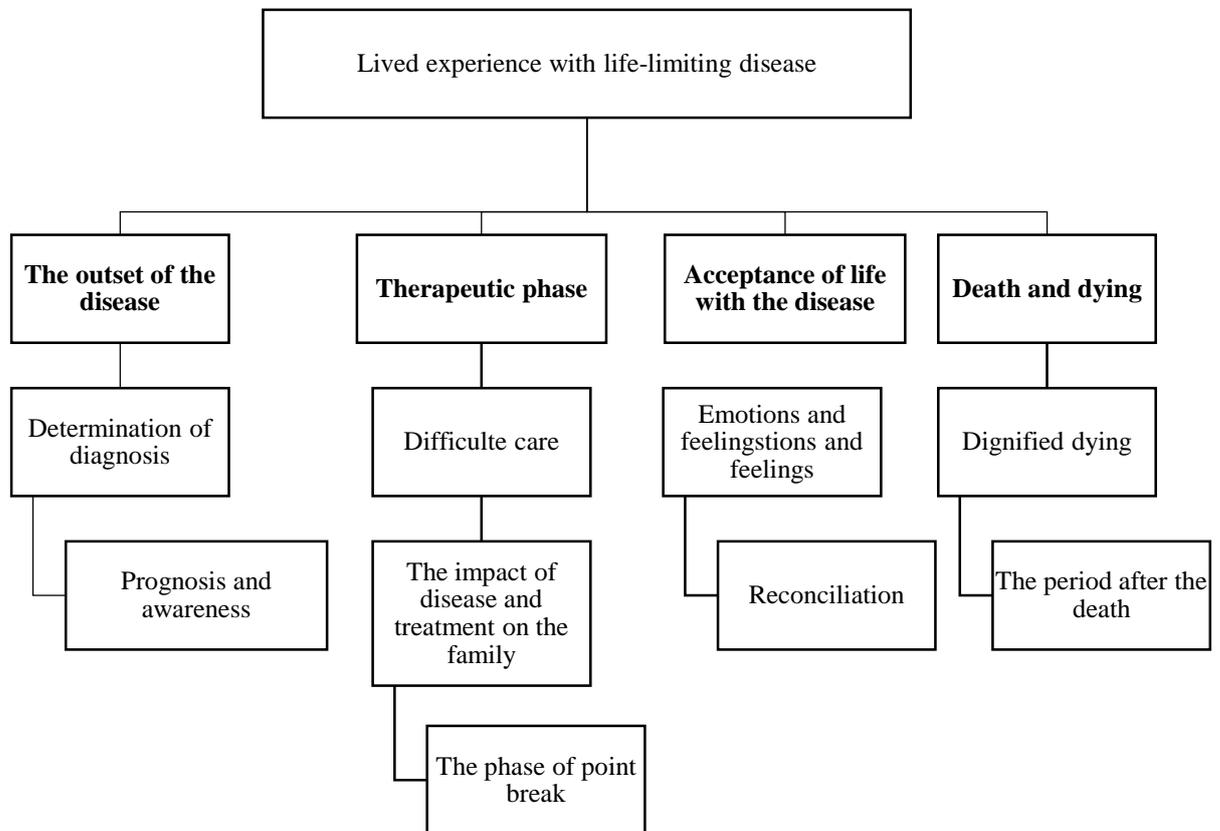
Interviews were recorded, carefully listened to and subsequently transcribed verbatim. The transcribed data were repeatedly analyzed in an attempt to understand the significance of individual statements and identify the nature of communication. The method of text coloring helped to mark key passages of conversations that involved research objectives. Procedures for break down and conceptualization in the frame of open coding allowed statements to assign terms that generally summarized what respondents expressed by specific words. Many concepts were

repeated or were almost identical and could thus be grouped together as a single concept. In the next step, axial coding was performed, in which the individual concepts were grouped according to similarities. If in some groups it was possible to find an analogous context, they were grouped and labeled by the higher concept. Using this procedure has been in the analysis of data specified the principal categories and subcategories. Categories were organized into an analytical relationship as per paradigmatic model. This relation is as follows: “A (conditions) leads to B (phenomenon), which leads to C (context), which leads to D (action or interactions including strategy), which then lead to E (consequences)” (Strauss, 1999, p. 92). In this particular case it is the following:

Diseases of Child (A – condition) leads to certain parents’ experience of life-threatening disease (B, phenomenon = central category), which leads to a certain experience during curative treatment (C), and subsequently to action – Adoption of life with the disease (D), whose culmination is the result of disease – death of the child (E). Direct statements from participants are given in italics.

Results

Four main categories were defined, based on data analysis. Each category and subcategory is shown in schema 1.



Schema 1 Overview of created categories and subcategories

The outset of the disease

Determination of diagnosis

In the process of determination of diagnosis there was a difference in the description of parents of children with cancer and non-cancer disease. Two children with cancer were diagnosed relatively early. Susan recounted a negative experience: *“They called us in and he just walked out and gave us the thumbs down.*

Eventually, he added: ‘Well, you should start working on a new baby’”. A similar experience is also mentioned by Radka, whose son was on MRI for knee pain: *“Afterwards some doctor from orthopedics called and said, ‘I just wanted to tell you, that Johnny’s life is in danger.’ Without introducing himself or saying anything concrete...”.*

The experience of respondents with determination of diagnosis in non-cancer diseases was characterised by long waits, unclear information, recurrent life-threatening states of the child, hospitalization and various examinations.

Prognosis and awareness

Determining diagnosis goes hand-in-hand with prognosis. If a percentual value of survival was known, it was truthfully communicated to some respondents. Reactions were mixed: *“They found out that she is suffering from a disease in which the muscles gradually atrophy and these children die due to suffocation. [She] ... has the most severe form. Neurologists told us that it’s 99% certain she will die within a year. After hearing this, my wife was completely devastated. She nearly collapsed”*. (Peter) The mother of a cancer boy recalled: *“After surgery they were walking around on tiptoes for three days Then the doctor came to us and told us that he had bad news ... that it was a malignant neuroectodermal tumor – that he would try to treat it and if we wanted some percentage, it was about 20%. So we said yeah, that’s great! We believed that he would cure him”*. (Susan) A characteristic phenomenon in cancer group respondents was confidence in the conduct of doctors and faith in a miracle cure. One of the mothers with hindsight evaluated her stance regarding the communication of diagnosis and repeated prognoses: *“We did not understand it at all. We were like two people from outer space, with blinkers. We were short-sighted, because we did not read the signals that the doctors were trying to give us. They always said it was ‘serious’, that ‘he could die’. And even though our doctor said a week before his death that he had just a 0.05% chance of being cured, we still said: But you will cure him anyway”*. (Radka)

Caring for children with non-cancer diseases with uncertain course brought to light problems caused by lack of information about diagnosis and prognosis: *“The information was about nothing. But for me it is better to know everything straight.... he will sit, he will not sit, he will live, he will die ... ”*. (Lida) Vera said: *“Nobody told us to prepare for the worst, that it might turn out badly. Absolutely nobody”*. For this reason they sought information from other sources: *“At the time I did a lot of studying and reading, looking for information, but now we’ve given up on it”*. (Simona) Other mothers regarded this activity in a very negative light. *“You can’t imagine how bewildering it is when you have to do it all by yourself, when you have to search for information in the literature, on the Internet. The papers from the doctor won’t tell you*

anything – you can’t understand it, especially as a layman”. (Vera)

Therapeutic phase

Difficulty care

With the exception of one case, care was provided by close relatives, either at home or in hospital, the environment alternating according to the current state of health of the child. Although demanding, home care was still preferable to carers: *“I have always tried to stay at home as much as possible. Of course it was always a problem for the family. But I just had a feeling that if she stays home it will balance the medical care and the psychological losses which hospitalization causes”*. (Simona) With hindsight, Vera evaluated the care she managed to provide at home as unbelievable: *“We were worrying about Kristýnka all the time... Actually, till approximately 21:00 I was busy with the kids, then I started to cook for the next day, then I did some laundry, and some late shopping in the evening, and around midnight I fed Kristýnka again till one o’clock in the morning. Then maybe till four o’clock a little bit of sleep and then the same over again”*.

Life-threatening disease always carried with it the chance of critical conditions developing and there was always the ever-present threat of the child's death. Thus, parents' stress levels increased: *“If your child stops breathing several times a day, and you do not know whether, when you put him to bed in the evening he will be able to breathe or whether you can afford to fall asleep for three hours, it’s a really awful responsibility ...”*. (Vera) Also in imminent threat of death was another child: *“She stopped breathing at home....Mum managed to resuscitate her. She grabbed her legs, slapped her back, and she was back. Then they told us that it happens to one in a hundred, maximum”*. (Peter) Unrelievable pain is another difficulty of care: *“I spent days just carrying her around. Kristýnka permanently screamed and the only position in which she found some relief was when I held her to myself. So I carried her like this some 16 hours a day, for a year and a half”*. (Vera)

The impact of disease and treatment on the family

Carers unanimously stated that the disease affected the functioning of the whole family. In some cases it had an impact on the relationship between the parents of the child: *“There were a few tense moments when I sensed that we would have a row simply because the agitation in the family was building up”*. (Vera) A solid relationship and mutual understanding between partners was reported as one of the most important factors in helping them cope with the situation: *“My husband bore all with me. I did not feel so bad,*

because he showed me that he still valued me, that he was always there beside me. These are very important things". (Susan)

The severity of the disease also affected the psychological state of the respondents. Vera stated that: *"The first years I didn't know if I shouldn't just drive the car into the first lamp post. The sorrow is so awful, nobody can imagine it."* The siblings also found themselves in a difficult position: *"We older children were completely pushed to one side. At that time we were supposed to help out and we were regarded not as children, but just as so many helping hands"*. (Helena) Another problem was the prolonged separation of a second child from their mother: *"You could tell that one month had been too long for him. When he was told he should go with me to the hospital, it was obvious he didn't want to. He didn't just want to go for a walk with me any more, he now said he wanted me to go home with him?"*. (Simona)

As a consequence of child care there were problems caused by commuting to medical facilities, financial worries, and the impact it had on work and family life. Peter stated that: *"It causes such disruption to life. Nobody can imagine it.... Everything is complicated, commuting, your whole life is turned upside-down."* One of the mothers sacrificed her job so she could be closer to her sick child: *"I'm a little sorry that I left my field. I abandoned something that I had studied and worked for"*. (Simona)

The phase of point break

In both diagnostic groups the moment came to make one of the hardest decisions in life. In the group of children with cancer that moment was associated with the termination of curative treatment, and parents' effort to come to terms with the terminal stage of disease. Initially parents were incapable of accepting this fact. The mother of a deceased boy said: *"The doctor asked if we thought that it should continue, that we could simply stop it and no longer have to undergo even the chemotherapy. We were in shock. He was trying to make a suggestion, but I did not understand it then"*. (Susan) Radka had a similar experience: *"They had asked us earlier whether we wanted to take him home. Approximately 2–3 weeks earlier. But we didn't understand it"*.

The right time for the parents came somewhat later: *"Only later did we understand that there was no longer any need for further suffering, that there was no need for additional imaging"*. (Susan)

The child's wishes were also crucial to the parents: *"The doctor came to Johnny and asked him whether he wanted to go home. And Johnny replied: 'Yeah, I do.' I asked the doctor what he meant by it, if he was sending him home to die. He replied 'yes'. The most*

important thing was what Johnny wanted. Although we were terribly afraid, we took him home, please him". (Radka) For carers of non-cancer diseased children it is not possible to identify a precise moment in time when the final decision was made. In all cases, the process took years and the experience exacted a considerable psychological toll.

Acceptance of life with disease

Emotions and feelings

Respondents described the course of the child's disease as fluctuating between periods of hope and optimism, and moments of disappointment, fear and anxiety. Another method, alternative therapy, additional surgery or other positive proposals from physicians led to a surge of euphoria and the hope that the child would be cured: *"You become fixated on the idea that it will help, that if she has withstood so much, she can withstand this and everything will definitely turn out well. And then again comes a moment when everything breaks down"*. (Helen) This rollercoaster of alternating emotions is also described by Simona: *"You experience a sort of positive vibration when someone tells you that something is good, when the only thing you'd heard before is that everything is bad. So when an expert tells you that the brain is good, you say to yourself, well, everything is not yet lost"*.

During the period of coping with the disease respondents repeatedly experienced feelings of guilt and remorse over earlier actions. Some mothers even sought the origin of the disease in pregnancy. Women come to terms with feelings of guilt by themselves: *"It was necessary to get into that state and abandon the idea that I was responsible for it, that it was my fault. Still the shadow of doubt remains in me....."*. (Simona)

Coming to Terms With Death

Respondents first sought a cure for the disease. Only after some time did they learn to accept the incurable nature of the disease. Simona stated that: *"I really believed that I would cure him. Healers, reiki, acupuncture, I started to read a lot of spiritual literature and studied it... I was convinced that Vojta would get better and that I had to be the one to ensure it"*. Her coming to terms with incurable disease is described by Simona as follows: *"I take it in the way that what is good for him is good for us. And if he decides that he wants to leave, then I will respect that"*.

Dying and death

Dignified dying

Carers of children with cancer who died at home, likewise described the need for assistance and coordination of care in the home environment in the

last days and weeks: *“We were in contact with a doctor all the time, whenever we could call him”*. (Susan) Radka also remembers cooperation with a mobile hospice: *“They equipped us. They gave us oxygen, medication for urination, sleeping pills, patches for pain. They gave us the option that if anything happened or if we could not manage, that we could come any time”*. Cooperation with the mobile hospice was not only a great support in this period, but in some families, essential in helping them deal with the situation: *“We called the doctor to do something that we couldn’t cope with any longer. So he arranged for the nurses from the mobile hospice to come within half an hour. They visited us three times a day. It really helped us. It recharged us physically and psychologically”*. (Radka) Such assistance enabled parents to regard their child’s departure as dignified. Helen spoke of the poor management of pain in her dying younger sister when they were not able to use hospice services: *“Her condition greatly deteriorated. She was completely emaciated, had a bloated belly and was in tremendous pain. No one cared how we were coping. This waiting for death, it was the most difficult...”*.

Participants commented favorably when given the opportunity to be with their child during the last moments of their life, at home: *“We managed to say a lot of things. We came to accept that you can’t say ‘don’t die!’ but ‘go the way you want to’, that he can just leave whenever he wants. Then to have your child in your arms...”*. (Susan) A similar experience is described by Radka: *“The last day all three of us slept together. I think he was satisfied and happy that he was at home. His departure was peaceful. A nurse from the hospice just came... She walked into the living room and Johnny breathed his last. He waited for her. He had loved us so dearly and did not want to leave us in that situation alone. He waited for a person who knew how to cope with it”*. Monika, whose child died in the ICU stressed the importance of the degree of sensitivity with which the death is communicated and of personal contact with the doctor: *“I appreciated the fact that the doctor came, because originally she was just going to give us a call. When she then came to say that the boy had died, the only thing I remember is that she said that she had made a cross on his forehead at least, as we had wanted him to be baptized. I thought it was very kind of her”*.

The period after the death

In the period after the death two common elements were important for the carers: the need for physical contact with the deceased and the need to preserve dignity and piety. In two cases both needs were met, while in another two cases they were not. Monika,

whose child died in hospital, and who did not have the opportunity to see him and hold him, said: *“I regret so much the fact that I could not hold him in my arms. I never had the physical contact. Not even at the funeral. I did not even think of it. If someone had asked me if I wanted to [hold him], I would have done it”*.

This experience was shared by Peter: *“I wanted to go to pathology, but it was a problem for them and they did not want to show me my child...”*. Susan describes the immediate moments after death at home as follows: *“We were not in a rush. I knew that I could keep him in my arms. We were together. We dressed him and washed him, calmly”*. Even in the other two cases, the first minutes after death were characterized by the following words: *“no hurry and no rush”*. Radka describes a state of helplessness immediately after the death of her child. However, nurses from the mobile hospice provided them with the necessary assistance and support: *“The nurse arranged everything and called everywhere. She bathed him, changed his clothes, taped his eyes, tied his little mouth. I sat with him and held his hand. He had his favorite pillow and toy”*.

For the bereaved the quality of the first meeting with the medics and undertakers following death was key to preserving the dignity of the deceased child: *“Above all else we required that an autopsy not be carried out. My husband took our child and lay him in the coffin. The coffin was awful, just for transport. We also needed to know that nobody would do anything to him anymore, that we did not need to worry. The parents need to know that nobody will touch their child anymore”*. (Susan)

Failure to comply with even the most basic principles of decency and professionalism was experienced by one respondent after the death of her sister: *“The doctor arrived, opened the door and said: ‘Where is it?’ He was disgusting, unpleasant. I had an argument with him. We told him what time she had died, and he said: ‘You mean to tell me that you left her lying around?’ I threw him out. Then another doctor arrived”*. (Helen)

Some participants, such as Monika, complain of inappropriate responses from neighbors after their child’s death: *“She told me: ‘Thank you for another little angel in heaven.’ As if it was my job to put little angels in heaven. That really got to me”*. Radka met with the following reaction from a neighbor: *“Oh dear, what a thing to happen to you! Well, you know, your grandparents didn’t have the chance to spend any time with him, so they called him up to heaven”*. She experienced another inappropriate response from a friend: *“Radka, now you’ll never be a grandmother ...”*.

Discussion

This qualitative research aimed to determine the life experiences of carers of children with life-threatening or life-limiting disease, which, in some cases resulted in the child's death. From the statements, it is clear the onset of incurable disease in a child subjects families and the sufferer to a long and distressing ordeal. How they come to terms with serious disease, and how they cope with the real threat of death, and the reactions they have to loss, are completely individual. Receiving a serious diagnosis for a child represents a profound shock, especially for parents. Acceptance and management of disease is particularly difficult when a child is born severely ill. Long-term uncertainty exists over whether the child will survive, and how they will be affected. Breaking the news of serious illness is a daunting task for physicians. However, information should always be provided as soon as possible (Řičan, 2006, p. 69) Respondents' experiences of regarding communication of diagnosis were varied. Parents of children with non-oncological disease waited long months for a final diagnosis. Although they suspected that there was something wrong, they nevertheless experienced shock and astonishment on actually receiving the diagnosis. A common feature of diseases with long-term adverse developments is their uncertain prognosis. The adaptation of the family basically never ends because every deterioration in the course of the disease means another new setback for the family (Řičan, 2006, p. 74). Parents of children with oncological disease were given clear and accurate information, including the chances of survival as a percentage. Even the faintest hope bolstered parents' faith in a cure and gave them the strength to continue fighting the disease.

A sick child is a very significant factor, which for a temporary or prolonged period forms and shapes the family system (Fendrychová et al., 2005, p. 33). Life-threatening disease in their child meant the beginning of a process of change for the respondents and their families. All experienced a stage of reorganization and a new arrangement of personal and family life. All efforts from then on focused on caring for a sick family member according to the current status of the child or the type of ongoing treatment provided both at home and in hospital. The illness of a child causes a variety of changes in broader social relations (Fendrychová et al., 2005, p. 33). Carers in all cases tried to be on hand for the child throughout the duration of the disease. In some cases they had to deal with issues related to absenteeism from work, and consequently, the financial situation of the family. With each statement an effort was made to establish a turning point in the acceptance of the incurability of

the disease. In tumorous diseases, that moment came when doctors proposed the ending of aggressive curative treatment and the acceptance of this by parents. Analysis of respondents' statements confirmed that one of the prerequisites for successful management of this situation is that the reason for the transition from curative to palliative treatment is made clear to the parents and is accepted by them (Lokaj, 2010, p. 110). With older children, the opinions and wishes of the child may contribute to the final decision, as was the case with one of the respondents. For parents of children with non-oncological disease the situation was much harder to manage. Carers became acquainted with the disease gradually over many months or years. Often unaware of the specific diagnosis, they had to cope with acute problems and life-threatening conditions. They underwent repeated hospitalizations, check-ups, treatments and surgery. Statements revealed that, because of the uncertain future course of the disease, their thoughts ranged from the most optimistic variant to the gradual acceptance of progressive incurable disease. Parkes, Relf and Couldrick (2007, p. 82) states that the most important task is to ensure that from the determination of diagnosis, the family receives uninterrupted care from at least one professional carer for as long as it is needed. Participants in our research did not have anyone like this available and care was thus fragmented and uncoordinated. From the start, the family should have at their disposal a key coordinator of care who can ensure continuity of care and guarantee that care is provided in accordance with the aims and wishes of the family and the child (Burkertová, Nováková, Dvořáková, 2005, p. 20; Inglin, Hornung, Bergstraesser, 2010, p. 1031-1038).

All real-life stories of dealing with incurable disease and, in some cases, death are accompanied by a retroactive reassessment of previous decisions, behavior or conduct. Typical is finding fault in others, hostility and anger directed towards the whole world, but also feelings of guilt. Self-blame often has its roots far back in the past (Řičan et al., 2006, p. 69). Close relatives of children most often mulled over procedures carried out by physicians, painful or devastating interventions and the period of pregnancy. For every family the period of dying is difficult. All the demands of care combine with unclear expectations (e.g. when death will occur and what precise form it will take), and stem from a lack of knowledge, and inexperience (Haškovcová, 2007, p. 79–80; Kübler-Rossová, 1994, p. 76). All carers expressed the need for coordination of palliative care at home during the death of a child. Parents frequently needed advice on how to deal with food rejection, inability to comply with drinking regimes, pain, and

personal support. Several studies (Contro et al., 2004, p. 1248–1252; Heller, Solomon, 2005, p. 335–346; Meyer et al., 2002, p. 226–231) have attested that regular contact with a health facility and its staff is perceived by parents as their main social contact and that its termination after the death of the child is regarded as a loss (Inglin, Hornung, Bergstraesser, 2010, p. 1034–1036; Sláma et al., 2011, p. 317–318). The bereaved parents should therefore remain in touch with health professionals even in the first phase after the death of a child. Of central importance in the first minutes after the child's death was the need for physical contact between the parent and child. Smaller children were held in their arms, or they held the hands of older children. When the death of a child occurs in a medical or other facility parents must be given the chance to make physical contact with the deceased child. They should be allowed to stay with their child's body for as long as they wish. Parents from whom children were taken away immediately after birth and were not able to hold them in their arms, or at least touch them, experience grief far longer. Medical personnel should, therefore, not underestimate this need nor should they neglect it or try to discourage it, as already mentioned by one of the mothers in a statement. In fact, it should be actively encouraged as the parents themselves may not realize their need for it at the time (Kübler-Rossová, 2003, p. 38; Parkes, Relf, Couldrick, 2007, p. 118).

The quality of the first meeting with medics and undertakers following the death of a child is one of the key factors in preserving the dignity of the deceased. Parents put great emphasis on not wishing to have an autopsy performed on the deceased child, which they considered unnecessary, and, moreover, a type of desecration.

The final leave-taking itself took several forms. Some of the bereaved gave their child a favorite toy or pillow. One parent took the small body of his child and lay him in a coffin. The most important thing for them was the assurance that nothing bad would happen to their child after he was taken from home. Everyone involved in the death of a child should be made aware that what happens from the time the child passes away until the funeral is extremely important to parents. They begin to realize that they can no longer protect their child, and thus need verbal assurances that their integrity will be respected.

Conclusion

Life-threatening and life-limiting illness in a child is especially difficult for parents, causing overwhelming stress and fear, and bringing severe disruption to family life. Children and their families need

psychosocial support, which consists mainly of consultation and requires the exercise of empathy and open communication.

Confronting the death of a child is one of the most difficult moments in the life of families, but also in the professional life of health professionals. Families should receive adequate support. Hospice care was provided only to families of children with oncological disease. Children with non-oncological diseases represent an important group for palliative care because their disease has a chronic and unpredictable course and the process of adaptation of the family is never completely finished. Families repeatedly find themselves in a crisis in which they do not have any systematic support system.

Ethical aspects and conflict of interest

The research complies with recommended ethical rules. The participants were informed of the objectives of the study and signed an informed consent. During the conversation they were not obliged to comment on any areas they found uncomfortable or too painful, furthermore they could suspend or terminate the interview at any point. The anonymity of respondents was preserved.

The authors declare that they are not aware of any conflict of interest.

Author contribution

Conception and design (RB, AK), data analysis and interpretation (RB, AK), manuscript draft (RB), critical revision of the manuscript (RB, AK), final approval of the manuscript (RB).

References

- Burketová H, Nováková D, Dvořáková J. Zdravotně sociální aspekty paliativní péče u dětí. *Kontakt*. 2005;7(1–2):17–23. (in Czech)
- Contro NA, Larson J, Scofield S, Sourkes B, Cohen HJ. Hospital staff and family perspectives regarding quality of pediatric palliative care. *Pediatrics*. 2004;114(5):1248–1252.
- Craig F, Abu-Saad Huijjer H, Benini F, Kuttner L, Wood C, Feraris PC, Zernikov B. IMPaCCT: standards for paediatric palliative care in Europe. *European Journal of Palliative Care*. 2007;14(3):109–114.
- Davies B, Sehring S, Patridge JC, Cooper BA, Hughes A, Philp JC, Amidi-Nouri A, Kramer RF. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics*. 2008;121(2):282–288.
- Fendrychová J. *Péče o kriticky nemocné dítě*. Brno: Národní centrum ošetrovatelství a nelékařských zdravotnických oborů; 2005. (in Czech)
- Heller KS, Solomon MZ. Continuity of care and caring: what matters to parents of children with life-threatening conditions. *Journal of Pediatric Nursing*. 2005;20(5):335–346.

- Hill K, Coyne I. Palliative care nursing for children in UK and Ireland. *British Journal of Nursing*. 2012;21(5):276–281.
- Huijter HAS, Benini F, Ferraris PC, Craig F, Kuttner L, Wood Ch, Zernikow B. *Palliative care for infants, children and young people – the facts*. EAPC: D'Ovidio Onlus; 2010 [cited 2014 Aug 14].
- Inglin S, Hornung R, Bergstraesser E. Palliative care for children and adolescents in Switzerland: a need analysis across three diagnostic groups. *European Journal of Pediatrics* 2001;170(8):1031–1038.
- Knapp C, Woodworth L, Wright M, Downing J, Drake R, Fowler-Kerry S, Hain R, Marston J. Pediatric palliative care provision around the World: A systematic review. *Pediatric Blood & Cancer*. 2011;57(3):361–368.
- Kübler-Rossová E. *O dětech a smrti*. Praha: ERMAT Praha; 2003. (in Czech)
- Lokaj P. Paliativní péče u dětí s nádorovým onemocněním. *Paliativna medicína a liečba bolesti*. 2010;3(3):110-112. (in Czech)
- Meyer EC, Burns JP, Griffith JL, Truog RD. Parental perspectives on end-of-life care in the pediatric intensive care unit. *Critical care medicine*. 2002;30(1):226–231.
- Monterosso L, DeGraves S. Paliativní péče v pediatrii. In: O'Connor M, Aranda S, editors. *Paliativní péče pro sestry všech oborů*. Praha: Grada Publishing; 2005. p. 275–284. (in Czech)
- Parkes CM, Relf M, Coultrick A. *Poradenství pro smrtelně nemocné a pozůstalé*. Brno: Společnost pro odbornou literaturu; 2007. (in Czech)
- Říčan P. *Dětská klinická psychologie*. 4. vyd. Praha: Grada Publishing; 2006. (in Czech)
- Sláma O. *Paliativní medicína pro praxi*. 2. vyd. Praha: Galén; 2011. (in Czech)
- Strauss A. *Základy kvalitativního výzkumu: Postupy a techniky metody zakotvené teorie*. Boskovice: Albert; 1999. (in Czech)
- Student JCh, Muhlum A, Student U. *Sociální práce v hospici a paliativní péče*. 1. vyd. Praha: H & H Vyšehradská; 2006. (in Czech)
- WHO definition of palliative care. World Health Organization. ©WHO; 2013 [cited 2014 Feb 24].
- Zemřelí 2012. *ÚZIS*. Institute of health information and statistics of the Czech Republic. [cited 2014 Dec 15]. Available from: <http://www.uzis.cz/publikace/zemreli-2012>