

LIVING “DAY-BY-DAY”: PARENTS’ EXPERIENCES DURING THEIR CHILD’S ACTIVE CANCER TREATMENT

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Abstract: *The aim of this study was to explore the experience of parents whose children are in active treatment for various types of cancer. Semi-structured interviews were conducted with 11 parents. Through interpretative phenomenological analysis, five themes were derived: a) response to the diagnosis, b) parental “navigating” through the new life situation, c) “being in the hospital”, d) sources of additional “burden”, and e) those who made the process of treatment easier. The majority of parents used active coping strategies; for example, they tried to mobilise existing resources, focused on the present and lived a “day-by-day” kind of life. As aggravating circumstances of treatment, they noted inadequate physical conditions, increased costs of living, inadequate support of family members and a prejudicial environment. During the process of medical treatment, parents found the following factors helpful: child’s strength, other parents’ support, community members, and the expertise of medical staff. This paper emphasises the complexities and importance of understanding parenting processes that can operate throughout the disease trajectory for families experiencing paediatric cancer. The findings on the experience of parents gives increasing insight into difficulties but also into parental protectiveness, which can contribute to defining the interventions for strengthening their parental role.*

Keywords: *cancer, children, parenting, coping and adaptation*

INTRODUCTION

Despite significant advances in its treatment, childhood cancer still poses a threat to children’s lives and is a prototype of a stressful life event affecting the whole family. In 2017, 133 children in Croatia were diagnosed with malignant diseases, which are considered the second leading cause of death among children (Croatian National Cancer Registry, 2020). Faced with life-threatening illness in their child, parents must cope with demanding medical treatment, characterised by frequent clinical appointments, administration of medications, monitoring side effects, maintenance of the child’s intake of food and fluids, and multiple hospitalisations (Pöder and von Essen, 2009) but also with significant changes in family relationships, roles, responsibilities, rituals, the loss of family normalcy, and the feeling of homelessness, uprootedness and instability (Schweitzer, Griffiths and Yates, 2012; West, Bell, Woodgate and Moules, 2015).

Parenting in the context of childhood cancer often requires an indefinite adjustment, as treatment and the added concerns about late medical and psychosocial effects of disease and treatment often continue several years after diagnosis (Williams, McCarthy, Eyles and Drew, 2013). Parents’ perceptions of self and family functioning are influenced by the illness (Pai et al., 2007) and, in the circumstances of uncertain and unpredictable treatment, the family is constrained to find new ways to function. Previous studies show that families have to make an effort to cope with the treatment and the side effects related to hospitalisation and pursuit of other life activities (Woodgate and Degner, 2003; Enskar, Hamrin, Carlsson and von Essen, 2011). They must adapt every day to the changing impact of potential side effects, complications, and the emotional needs of both their child and themselves (Yeh, 2003), adjusting by organizing their family roles and by relocating responsibilities among other family members (McCubbin, Balling, Possin, Frierdich and Bryne,

2002; Nicholas et al., 2009), thus creating a family lifestyle known as “living as a split family” (McCubbin et al., 2002; McGrath, Paton and Huff, 2005). They must maintain household demands and arrange vocational time at work (Woodgate and Degner, 2003; Norberg and Steneby, 2009), as well as balance the needs of the ill child with those of other family members (McGrath et al., 2005). The parents can meet these demands more easily if they have social support provided by their friends, colleagues, other parents whose children are receiving treatment, family resources (a good partner relationship, religiousness, family cohesion, attachment, flexibility, mutual understanding and open communication), and other community resources at their disposal (support from school, information support from health care workers) (Schweitzer et al., 2012; Russel, Bouffet, Beaton and Lollis, 2016).

Despite the highly stressful life situation, mostly qualitative research findings indicate that some parents perceive positive changes in the family, which are the result of the child’s disease (Quin, 2008; Schweitzer et al., 2012). The aforementioned changes reflect the reevaluation of the meaning and purpose of life and an attempt to redefine themselves, often in terms of priorities, relationship and sense of community, and to achieve a certain level of optimism and altruism (Schweitzer et al., 2012). In the research of Russel et al. (2016), parents point out that they shift the focus away from the illness and grief towards enjoyable activities and survival, thus shaping and appreciating their lives together in a new way. In the research of McCubbin et al. (2002), parents affirm that they appreciate each day even more than they did before, which gives them an opportunity to be less preoccupied and worried about less important life problems. They also point out their “willingness to live their life in the moment” and their deep attachment to their child.

Taking into consideration the outlined problems and considerations, as well as the lack of empirical development of this field in Croatia, the present research grew out of the fact that understanding the parents’ experiences requires personal experience and understanding of the disease, as well as the social context in which this experience takes place. The unpredictability of treatment, as an integral

part of that context, could explain why parents feel that their ability to cope with the diagnosis and treatment fluctuates throughout their experience (Yeh, 2003). As a result, we conducted a phenomenological study to increase our understanding of the process that parents go through when taking care of their child with cancer during active treatment, and to explore how parents give meaning to their experiences. The voices of parents are one of the vital components for health professionals and for public sensibilisation to the needs of these vulnerable populations.

AIM

The aim of this study is to gain a deeper understanding of parent experience and the meaning ascribed to being the parent of a child who is in active treatment for cancer.

METHOD

Participants and Recruitment

The sample consisted of parents who had children in active treatment for a variety of childhood cancers. Children were undergoing active treatment for their cancer within approximately six months since diagnosis through the oncology unit of a children’s hospital. The sample was purposeful. Parents were excluded from the study if their child was in a terminal phase of the illness and was hospitalised in the palliative care unit. Participants were recruited by two oncologists and nurses from the Department for Haematology and Oncology at Children’s Hospital Zagreb, before the Department moved to another hospital in June 2015. They contacted parents in person to invite them to participate. If they agreed, authors contacted the parent in person to obtain written consent after providing more information about the study. Eleven parents (eight mothers and three fathers) participated in the study. The age range of the interviewed parents was between 24 years and 48 years (mean age, 36 years). Five of the children were female and six were male. The age of the children ranged from 1 to 16 years, while the age of the children at diagnosis ranged between 1 and 15 years of age. The children had been off treatment for 20–38 months, and they differed in type of cancer. The children’s

diagnoses included acute lymphoblastic leukemia, brain tumor, tumors of the peripheral nervous system and bone cancer.

Data Collection

A semi-structured interview was used for data collection. Parents were asked to describe their experiences of living with a child with cancer and its effects on family life, with the focus on social and psychological processes related to treatment and diagnosis. The interview was divided into several thematic sections: a) experience of the child's diagnosis, b) the cancer adjustment process and family relationships in other child-family and parent-parent interactions, d) family routines, e) social support and family resources, f) hospital stay and g) perspectives on the future. Data were collected for the period during diagnosis and treatment. The interviews were conducted by the authors in the hospital or in a public location near the hospital at a predetermined time suitable for the participants. The interviews lasted 1-1.5 hours and were audiotaped and transcribed verbatim.

Ethical Issues

The study was approved by the ethics committee of the hospital. Each of the participants signed an informed consent form and received an invitation letter, an abstract of the study proposal and a consent form allowing the participant to respond and demonstrate a desire to be considered for the study. Each participant received a copy of the written consent and contact information for a counselling service. Participation was voluntary. The participants' names and other identifying information have been removed to preserve anonymity and protect confidentiality.

Data Analysis

Data were analysed using interpretative phenomenological analysis (Smith, Jarman and Osborn, 1999). Analysis involved the following steps: (1) each transcript was read several times and in-depth, noting all examples of meaning, comments and views; (2) these examples were then identified and grouped into preliminary themes; (3) themes were further grouped together into clusters; and (4) tabu-

lating themes were shown in a summary table. The process of collapsing themes into super-ordinate themes involved reading the content of interview data and finding common clusters and concepts as well as the overall messages that were emerging. Transcripts were independently coded by a second researcher, and discrepancies were resolved by discussion. The process was ongoing and iterative, with continuous referral to the raw data.

RESULTS

Five themes emerged from the data on the parents' descriptions of their experience: (1) response to the diagnosis, (2) parental "navigating" through the new life situation, (3) "being in the hospital", (4) sources of additional "burden", and (5) those who made the process of treatment easier.

Response to the diagnosis

Parents reported that first symptoms they noticed were general weakness, pain in different body parts, a lasting high fever or accidental injuries. Parents' reactions to the diagnosis were shock, disbelief, denial, anger and a sense of questioning their own responsibility. One father described it in these words: *(It was a big shock. I don't even know how I drove myself from X to Y. These two 'movies' I don't even have in my head. All I know is that I didn't feel my legs at all.. (3))*. One mother said that three weeks after the beginning of treatment, she was hoping that the doctors would tell her that they had made a mistake and there was nothing wrong with her daughter. Only two mothers have said they intuitively thought, "This could be leukaemia". The "key moment" when the majority of parents became aware of the cancer was hair loss as a side effect of chemotherapy. One mother illustrated how cutting her child's hair was emotionally too demanding an act and that others did it instead of her. She said: *(I didn't have the heart to cut off her hair. She had beautiful long hair and I couldn't do it because I felt horrible. At that moment, I was collecting her little hair and now I have a bag of it, to which my husband told me, 'You're crazy! Why do you want that?!' However, I couldn't detach myself from it! Because here is where the first symptoms show that it's here and you don't have the strength for it... (6))*.

Parental “navigating” through the new life situation

Parents used mainly active coping strategies with their child’s cancer. These strategies were grouped into three themes: engaged actively in the treatment, focusing on the present (living “day-by-day”) and accepting the existing situation. Three parents indicated that their faith in God, optimism and hope represented a way of dealing with the current life situation. Only one father expressed avoidance of his daughter’s illness. He perceived himself as weak and depressed, prone to withdrawal and avoiding contact with other people. Engaging actively in treatment meant focusing on demands of treatment protocol, seeking information and relying on one’s own strength. One mother said: (*...When I’m in the hospital, we’re here, we do the planned therapy, it goes fast, we go home, charge our batteries, go back to the hospital and go all over again and so it goes...and we still have a lot of chemo to go through, it’s a big programme because of the difficult type and degree of the disease... (8)*).

Parents were seeking treatment-related information from health care providers or other parents. One mother said that she read many books about her daughter’s cancer. Because of the large amount of information, some parents avoided seeking information from the Internet. Most of the parents were trying to rely on their own strength. One mother described it this way: (*...If you don’t help yourself, all those psychotherapists don’t mean anything... of course it’s great, that positive support is great, but it’s essential that you find your way out on your own... (8)*). As treatment went by, they focused on the present and living “day-by-day”. Two mothers described their attempts to organise everyday life when they were not in the hospital, then trying to spend quality time with their family.

(*We don’t do some things when the immune system is bad and we all know that, but we all go and laugh and go out. We are happy with small things and we don’t look at the world with the same eyes as we did before, we live ‘day-by-day’... (2)*). Parents said that they have accepted the current situation after all, aware that they do not have influence on the final outcome of treatment or cancer

recurrence. They described it as “no matter how it ends, it will be how it has to be”. Despite that, they were still hoping for a positive outcome.

‘Being in the hospital’

“Overcrowded”, “swarming with people” and “terrible without any dignity” were the expressions parents used to describe hospital stays. They were all dissatisfied with poor accommodation conditions and quality of hospital food. All parents complained the most about two small hospital rooms, where children of the same gender and health status were accommodated. In those rooms, the children who needed palliative care and the children who were on active treatment were accommodated together. One mother argued that it could happen that a child is dying while the other children are watching. She said: (*...There is no dignity here because they don’t have a place for a dying child, so a child is dying among five of them and the children are watching. Do you know how terrible that is? (3)*). During the day parents spend time with their children, which one mother described as follows: (*...These are confined conditions. All of us tolerate each other there as much as we can. There are five different personalities with five different personalities of their children, which are 10 people at the same time. However, we all tolerate each other and it’s manageable, actually ok, we can endure (6)*). Parents also complained about insufficient numbers of beds and pillows for children who come to chemotherapy, inadequate sanitation, absence of separate departments for children who need palliative care and a living room or playroom. Parents perceived the lack of adequate accommodation conditions as lack of concern for children with cancer. They emphasised that, in the hospital, there should be a toilet and an appropriate room only for parents from the oncology department. One mother described this problem like this: (*We don’t have a place to sit down, you know, to have some room somewhere, something like a living room, you know, so maybe we could sit down. During the winter we don’t have anywhere to sit down, we can only freeze outside and catch an infection so we can’t be by our child... (8)*).

Besides accommodation, parents highlighted the problem of hospital food, which was not adjust-

ed to the child's health state. They proposed an individual approach to the child's hospital food in accordance with his or her health condition and a greater involvement of nutritionists in meal planning. Despite parental objections related to hospital stay, they were satisfied with health care providers. They perceived the oncologists as competent experts, under-paid for their job without adequate working conditions, and the nurses as people who provide care.

(...I think they are highly educated and I give them credit for that, but I think they don't have good working conditions. Another thing, it's a team of doctors, there are four of them, they know everything about all the patients, that's amazing... let's say, especially nurse XX, hats off to her, she really knows the medical history of each child, I mean, you come across her in the hallway, you don't even get a chance to introduce yourself, she knows everything about your child and all the doctors are really perfect (6)).

The fact that they could rely on another doctor who was also well acquainted with the child's diagnosis was important and helpful to the parents if their usual doctor was not in the hospital. There were various experiences of the parents concerning information availability from the doctors. One mother said that *(...it was difficult to get information about her daughter's health state, and she had to 'pull [doctors] by the sleeve'... (5))*. Furthermore, cooperation with doctors was described as problematic because of the use of medical language in communication, poor communication skills and lack of empathy.

Sources of additional "burden"

Parents described that child's treatment demanded a full change in family life. They needed to adopt new forms of family functioning, such as providing care for other children, and dealing with increased financial costs and demanding administration in the social security system. Some parents had to travel every day to visit their child in the hospital. All parents stated that the child's cancer led to increased life costs, for example, for accommodation (those who lived outside of the place of hospital treatment), transport, food and

additional nutritional supplements. Most parents cooked for their children and brought them food because the hospital food did not suit them, which was an additional source of costs. Families also faced difficulties regarding their employment status. One mother reported that she lost her job at the same time when her daughter got sick. They had the problem of paying off their home loan. Because of the reduced income, the family tried to save money in various ways, for example: *(Well, when she's in the hospital, we don't use the car, we go on foot or by tram instead, just to save gas those five days. Then you need to take her by car every day because of bad test results. You can't take her in a tram... (6)).*

The majority of the parents perceived the procedure of getting their rights from several social security systems as confusing and complicated because of bureaucracy, which they did not have time or energy to deal with. Mostly the other parent was occupied with getting various rights or both parents gave up. Certain behaviours of family, friends and strangers were also perceived as a source of additional burden. Parents recognised these behaviours as inappropriate reactions, the need for family members to be involved everyday in the treatment and to play the role of "consoler" of others. Parents perceived reactions from others such as *(I know how you feel' or 'Well...is it true that you're in pain? (7))'* (addressed to the child when staying at home) as a reflection of disregard for their situation. The parents perceived those behaviours as a lack of understanding for the nature of the child's cancer and their current life situation. One mother described a situation in which her son found himself. She said: *(...One morning he went to see his aunt in the shop because she always works late and then her boss saw him coming on the camera. He had no hair then. She knew the situation. She phoned her. She shouted and said that this kid mustn't ever come again because when people see him, they get frightened and don't want to buy anything. Imagine a child going through chemotherapy whom you have to tell not to come and see his aunt... (8)).*

Other family members' need to be involved every day in the child's treatment was burdening to the parents, because it took up their time and inter-

ferred with their everyday functioning. According to the parents, the relatives phoned every day or visited them at home (between periods of hospitalisation) and wanted to get informed about the child’s current health condition. Parents described that being the comforter to family members and friends was very exhausting for them. One mother explained how, after discovering that her child had a tumor, she did not know if the cancer was curable or not. However, she tried to convince her father who was crying because of his granddaughter’s cancer that (*...it is important that the cancer is curable... (7)*).

Those who made the process of treatment easier

Financial and informational support, grandparents’ care for other children, assistance provided by nongovernmental organisations (NGOs), organised money raising and understanding from co-workers, were perceived by parents as supportive actions. Family and community members were a source of support as well. To the parents, the most important sources of support were the child’s strength, partner, parents, friends, NGOs and other parents whose children also had cancer. One mother illustrated how her son, after finding out the diagnosis, said: (*...I know that you and I will beat this together... (2)*). Most parents did not look for psychological help; instead, they substituted it with support from other parents. They had the feeling that they understood each other immediately because they were fighting for the same thing”. This is how one of the mothers described it: (*...Why do we need a psychiatrist because we have each other and because simply, no psychiatrist will understand us as a parent understands another parent? When we look at each other, we know that something is not right or that everything is fine... (8)*).

Parents found grandparents’ support of great importance because they helped them by taking care of other children, preparing homemade food and providing financial support. Knowing that their other children were safe meant to the parents that they could focus all their efforts on the child with cancer. Free parking spaces, exemption from highway tolls and legal advice provided by NGOs were perceived by parents as a source of valuable

help. Two parents experienced that their friends, colleagues and others organised humanitarian actions and in these ways provided them financial support when they needed it.

DISCUSSION

Results indicate that there are varieties of parental experiences as they care for their child who is in treatment for cancer, and that some parents fare well, while others expressed significant changes to their health and life experience. For all the parents, their child’s cancer diagnosis was completely unexpected and sudden, and they did not assume that the initial symptoms of the change in their child’s health were actually the symptoms of a cancer. Their reactions when faced with the diagnosis were shock, disbelief, and denial. Such behaviours were also found in related studies (Banerjee et al., 2011; Bally et al., 2014) and they lasted for a certain period, depending on each parent. In the case of one mother, denial lasted several months, which is in line with the findings of the Boman, Viksten, Kogner and Samuelsson (2004), who showed that parents needed a great deal of psychosocial attention at the time of the initial shock, and that some parents needed this attention for a long period of time. These findings could be especially important for medical staff, as well as family and friends of the parents, who should avoid “rushing” the parents in the process of becoming aware of the disease, and who should show enough patience by giving them the time they need.

Parents, when faced with a potentially life-threatening illness of a child and uncertain medical treatment over which they have no control, see their former life turned upside-down overnight. In those new, changed life circumstances, the parents must look for a variety of strategies to cope with their children’s illness. Woodgate and Degner (2003) described the family’s experience of the child’s cancer path as “getting through all the rough spots” by trying to “keep the spirit alive”; it is a “continuous battle”, as Khoury, Huijjer and Doumit (2013) found in their study. In present study, most parents also used problem-focused strategies to cope. Similar to results of other studies such as Johns et al. (2009) and Kilicarslan-Toruner and Akgun-Citak (2013), parents tried to engage

actively in the treatment, focus on the present and accept the existing situation. Some parents showed religious beliefs as helpful towards children's cancer treatment, which was also found in the other studies (Brody and Simmons, 2007; Johns et al., 2009). One mother mentioned that finding out her child had a higher chance of surviving compared to the diagnosis of other ill children helped her cope with her child's illness, but she also stressed that this did not mean she wished something bad to happen to the other children. Schweitzer et al. (2012) found that this method of "comparing themselves to others" provided parents with a feeling of roundness. It is worth pointing out that uncertainty and uncontrollability are important components of the new situation that determines the coping process of parents of children with cancer. Uncertainty about the day-to-day course of the illness as well as about the long-term prognosis make it difficult to predict or plan anything. The present study revealed that one way that parents coped with the uncertainty, which was an inseparable part of the treatment experience, was to focus on fulfilling the treatment requirements and to live their lives on a "day-to-day" basis, reflecting their inability to make any long-term plans. In this life situation over which they have no control whatsoever, the parents need clear and unambiguous information adjusted to their needs (Kastel, Enskar and Bjork, 2011). The present study, they sought treatment-related information from health care providers, and they highlighted the importance of the way in which information was presented to them.

In the present study, the whole experience of a child's illness was revealed as complex and unpredictable, but not only for parents: there was a need for the whole family to undergo a process of adjustment. The cancer diagnosis led to a disruption in the daily family dynamics almost overnight, and as such required new forms of family organisation. Family life was running on two tracks during active treatment, and the duties of the parents were divided as well. Our observation of parental co-operation is aligned with previous studies that found that mothers and fathers share the responsibilities of caring for the ill child, other children, and managing financial status in order to overcome the situation (Bjork, Wiebe and Hallstrom,

2005; Saifan, Masa'Deh, Hall and Collier, 2014). In this study, mostly it was the mothers who took over the responsibility of caring for the ill child, while fathers took care of the other children and maintained active employment. The findings are in line with those of Wong and Chan (2006) and McGrath et al. (2005) who reported that mothers quit their jobs, had to take time off and stop participating in social activities during the period of care. Due to being away from home during active treatment, mothers are often inclined to express a conflict in their roles, because they are unable to be with their ill child in the hospital and with other family members at the same time (McGrath, 2001). Because of the treatment and separation of family members, the change in family life comes with increased financial costs and administrative demands, perceived by the parents as a waste of time and energy, which was also reported in other studies (Bjork, Wiebe and Hallstrom, 2009).

The highly stressful situation of the parents in our study was made more difficult by the conditions of hospital stay and certain behaviour of family members and friends. The parents had major complaints about the inadequacy of accommodation, hospital food, and the lack of space for parents. This kind of dissatisfaction with the hospital conditions was not found in other relevant studies. Before moving to another hospital in June 2015, the Department for Haematology and Oncology, where the children in this study were treated, consisted of two wards and a very small place for the medical staff. Parents, medical staff and NGOs have been warning for years about the inadequacy of conditions in the hospital. The parents elicited the lack of adequate hospital conditions as lack of care by the state for the most vulnerable group in the society. In its poor hospital facilities, Croatia can be compared with other East European countries (Kowalczyk et al., 2016). Parents in our study also gave clear recommendations for improving hospital conditions, ranging from simple ones (chairs in the hall for the parents, an extra window in the hospital room) to much more important ones, such as a larger number of rooms for a smaller number of children, separated in terms of child gender and current status of the disease. Their recommendations are in line with the minimum requirements

according to the European Standard of Care for Children with Cancer (2008). Every childhood cancer treatment centre should provide inpatient, day ward and outpatient facilities and residential facilities for parents and siblings, comprehensive information on diagnosis and treatment, comprehensive palliative care and social support for the child and their family at the time of diagnosis and throughout treatment (Kowalczyk et al., 2014).

Although the parents were dissatisfied with the abovementioned factors, the received competent medical care contributed to parents’ perceiving the hospital as a safe place. Similar findings were noted in other studies (Banerjee et al., 2011; Schweitzer et al., 2012). Outside the hospital, the parents faced certain unpleasant reactions, mainly prejudice and a lack of understanding of the nature and treatment of the disease. Lack of support during and after the child’s treatment may increase the risk of emotional distress among parents (Norberg, Lindblad and Boman, 2006). Despite the highly stressful and unpredictable treatment of their child’s cancer, some parents in our study reported positive family growth. Similar to previous findings (Flury, Cafilisch, Ullmann-Bremi and Spichiger, 2011), the priorities in family life changed: things that seemed to be important before lost their importance. The family felt that they appreciated things they had taken for granted earlier. Families shifted the focus of their vision for the future. They felt able to put the impact of other events into a proper perspective, and felt a need to live happily in that moment. They started to reflect upon what was most important in life. Other studies found that parents who have children in treatment for cancer found positive gains from their experience (Wong and Chan, 2006; Fletcher, Schneider and Harry, 2010), including strengthened relationships among family members (Brody and Simmons, 2007; Schweitzer et al., 2012) and reprioritising the time spent with their child (Brody and Simmons, 2007; Bally et al., 2014). The parents also perceive the support of relatives and friends as very positive and valuable. Similar to other studies (McCubbin et al., 2002; Brody and Simmons, 2007), parents in our study appreciated support from the community in the form of help with finances, childcare, emotional support, and home maintenance. A study by Singer

et al. (1999) indicates that this type of connection is a valuable source of assistance to make adaptations to having a child with an illness, making progress on dealing with specific problems and helping parents to become more effective at coping with the demands of parenting a child with an illness. This study revealed that some parents were reluctant to share their stories with their friends and relatives, but were willing, on the other hand, to share their feelings with other parents with similar experience in the ward. That was considered a very useful source of support, especially at the early stage of the illness. “Being in the same boat” meant for the parents that only parents of other ill children could understand them completely. Informal support provided by other parents replaced available professional help; it was given to them in the most acceptable way and it could be referred to as “tailor-made support for parents”. This is similar to previous results (Flury et al., 2011; Banerjee et al., 2011), which showed that exchanging experiences helped parents get through these difficult times.

LIMITATIONS OF THE STUDY

The limitations of this study are the result of the predominance of mothers over fathers and unforeseen circumstances during treatment that affected the parents’ participation. The research was more accessible to the mothers because they spent more time with their children in the hospital, while the fathers paid an occasional visit or stayed at home for work or to take care of other family members. Other studies also provide insights about the parents’ experiences of having a child with cancer from the mothers’ perspective, which indicates the need to conduct some detailed research in the future, which is focused on how the fathers deal with this situation. The doctors and the medical staff were first to invite the parents to participate in the research (i.e. those parents they considered able to participate), which was a great contribution to the research, but this form of selection might lead to bias in the choice of parents. The inability to control the course of treatment and frequent changes in the child’s health condition had an effect on the parents’ participation in terms of the time they could spend in the interview (often shorter than planned), their withdrawal from the study

(although they had agreed to participate in the first place), and their preoccupation about changes during the interview (e.g. surgical procedures, deterioration in health condition).

CONCLUSION

Understanding parents' experience and accepting their recommendations could increase sensitivity for parents' needs during the treatment and lead to more effective family functioning, and more comprehensive health and psychosocial care. The findings of this study contribute to a greater understanding of parents who have a child diagnosed with cancer, so there are implications for health care professionals. Highlighting a great number of treatment-related emotional and psychosocial challenges that parents navigate, these findings concur with the results of numerous studies in underlining the need for comprehensive medical care that incorporates psychosocial support for these pertinent issues. Accessible full-range care, together with a supportive environment, is crucial during treatment, but parents can also find it quite useful at the beginning (upon diagnosis), before they have adapted to the new life situation. The results of this study indicate that, after the initial overwhelming feelings, the parents eventually get hold of themselves and start using their own resources, and gain a potential for positive family growth, which can be useful for experts when planning, directing and implementing interventions in their

work with the parents. Furthermore, the findings also emphasise the importance of easily accessible administrative services, where parents can claim the rights to which they are entitled. This study also highlights the need for good communication based on professional awareness of how parents understand and experience their child's illness, as well as the importance of providing the parents information sensitively and individually to address their needs and requirements without unnecessarily increasing their anxiety or insecurity. The parents suggest that medical staff avoid incomprehensible medical terminology in their communication and that they be available and empathic. They point out the importance of providing dignified hospital accommodation (which was not the case in the ward where their children were being treated), because the difficulties that arise from uncertain treatment outcomes are already demanding and complex enough. However, the findings of this study clearly indicate that there is a need for educating the general public and making them aware of the nature and treatment of malignant diseases, as there is a lack of understanding of the nature of the disease, inappropriate reactions and demands towards the parents, as well as persistent prejudice towards the affected children. The importance of the implications listed above is particularly reflected in the fact that parents, together with a medical team, are the most important resource for children during medical treatment.

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