


Listening to Parents of Children With Cancer—Between Life and its end

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Abstract

This study aimed to explore and provide an in-depth insight into the experience and perceptions of parents to children with cancer at the end of life (EOL). A sample of 15 parents of children (aged 2-18) with cancer participated in semi-structured interviews in an oncology department of an Israeli hospital. Data were analyzed using a phenomenological thematic analysis approach. The findings that emerged revealed: (a) the cultural aspect of the Israeli society of the importance of family and of the children within the family, (b) the parents' unique way of coping, of holding a dual awareness, and (c) emphasizing that hope and support are necessary components for parents' ability to cope with their child having terminal cancer, at the EOL. A number of important practical recommendations can be made for professionals treating child facing the EOL with cancer and their families. First, understanding the "double awareness" developed by parents of children facing with EOL cancer. Second, there is significance to bring the medical staff closer to the patient's bed, which is to say, training medical staff in open communication on this subject. Third, it is recommended to construct intervention programs that would accompany the whole family and not just the parents. Fourth, there is some necessity to train healthcare teams working in pediatric oncology wards and providing palliative care, to teach them how to help people hold on hope and to evaluate hope in parents of children at the EOL.

Keywords

parents, children, cancer, end of life, experience, perceptions, hope, palliative care, social support

Introduction

The significant advances in cancer treatment in recent decades are responsible for the survival of approximately 80% of children and adolescents affected with cancer (1). Child facing the end of life (EOL) is a vulnerable time for the remaining 20% of young people and their families (2). In Israel every year approximately 450 to 500 new pediatric patients are diagnosed with various types of cancer, and approximately 90 to 100 of these children succumb to their disease every year (3).

Young oncology patients who are at the EOL stage may experience a number of symptoms, including pain, fatigue, and weakness. Research has indicated that approximately 90% of parents report that their child experienced a great deal of suffering from at least one symptom, while 50% reported that their child suffered from 3 or more symptoms (4). Even when these symptoms are treated, less than 30% of the parents reported that the treatments were effective and caused any relief in the suffering or pain/fatigue or weakness in the children.

Parenting a child facing the EOL is a complex and multi-dimensional experience that typically has a profound effect

on all areas—emotional, psychological, physical, and financial—of family life. It evokes anxiety and grief, and parents fear for their children's physical suffering, dependency, and vulnerability (5). A feeling of loss is a prominent factor for parents dealing with a child facing the EOL situation, and this leads to a struggle between maintaining the child's status and letting them go (6). Parents also undergo significant stress when forced into decision-making situations regarding treatment options (7).

During the child facing the EOL stage, parents experience both hope and hopelessness (6). Hope can ease the fear of losing a child and help maintain a harmonious parent-child relationship. In some cases, as a child's condition worsens, hope can also help the transition to a peaceful EOL (6,7).

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The extent to which parents are able to adapt to the challenges of facing EOL will greatly influence the manner in which a child will die (8).

Specialist pediatric palliative care services are promoted as an important component of palliative care for children, but as Taylor et al (9) stated recently, there is uncertainty about the professionals' roles and what they offer. For clinicians it is therefore imperative to know and better understand how parents experience their child's facing the EOL and what their specific needs are in order to provide good quality care. This study aimed to address these gaps by exploring the experiences of parents of a child facing the EOL with cancer.

Considering the abstract nature of this subject, the qualitative study of the experiences of parents can lead to a deeper understanding. Qualitative research provides a good opportunity to generate deep knowledge through the experiences of individuals (10) and facilitates the collection of data which provide an understanding of the meaning of phenomena from the perspective of individuals. Furthermore, the most suitable method for this study was a method that could illustrate the nature of the phenomenon in its natural context, along with its structure and the factors affecting its formation. Therefore, the present study was designed in a qualitative way.

Method

This study used a phenomenological approach through semi-structured interviews to reveal and provide an in-depth insight into the experiences and perceptions of parents in Israel who were experiencing a child facing the EOL stage of children with cancer. This approach enables systematic understanding of a complex, multidimensional, essentially difficult-to-measure phenomenon from the subjective point of view of the person experiencing it and is suitable when the researcher is interested in how participants understand and assign meaning to experiences in their lives (11).

To support the subjective point of view of each participant the study used theoretical framework of post-positivism. Post-positivists challenge the idea that there is 'absolute' truth of knowledge (12). This is especially true in this study, since the experiences of the parents are individual experiences, reflecting the unique circumstances and personal coping of each of the parents. The epistemology of post-positivism is objective, and knowledge is sought through replication (13), which is why this theoretical framework is appropriate, given the topic of this study.

Sample set

Participants were recruited from the pediatric oncology ward of a medical hospital in central Israel. Because of the complexity of the research topic, locating parents who would participate in the study had to be done with the greatest sensitivity. In this study, the process of recruiting parents to participate in the study included the following steps:

First, we put up a flyer introducing the study, at the Department of Pediatric Oncology. Second, parents who expressed interest in participating were asked to contact the first researcher directly, have a conversation with her about the study, ask any questions, and debate with her about all aspects of their potential participation in the study. Because of the sensitivity of the research topic, a decision was made that only one researcher—the first researcher, would manage and conduct all of the interviews with the parents. This decision was made due to the researcher's in-depth knowledge of the culture under investigation as well as the field of study—due to a long-term stay in the Pediatric Oncology Department during 2020-2021, for the purposes of conducting another ethnographic research. (The interviews that were conducted for this study are not part of the ethnographic study, but the researcher's in-depth acquaintance with the culture under investigation and the field of study, enabled the researcher and the study participants to establish a trust between them).

Eligible participants were those who (a) were caring for their child facing the EOL period, (b) had no diagnosis of mental illness, (c) were able to communicate in Hebrew, and (d) were willing to participate in this research study and provide written consent.

Fourth, out of the 18 parents who approached the researcher in the research field, not all agreed to be interviewed, and eventually 15 parents were ultimately recruited to participate in this study between January 2021 and July 2021 (Supplemental Table 1).

In addition, Supplemental Table 2 present clinical and demographic characteristic of the patients/children. The children were between the ages of 2 and 18 years at the time of diagnosis of the disease. Nine (60%) were male and 6 (40%) were female.

The interviews with the parents were concluded within a period of 3 weeks to 2 months before the death of their children.

In order to maintain the trustworthiness of the study, the study included trustworthiness.

Throughout the process, there was a strict adherence to the transparency of the research procedure with the parents. This transparency included: presenting the research topic, positioning the researchers in the field of research, a request for descriptions that are as detailed as possible from the research participants. Obtaining the approval for this research participants for the researchers' interpretation (the themes). In addition, throughout the entire study, it was accompanied by:

- (A) Writing a field note, which included a wide range of comments, such as: the researcher's impressions, the process of making research related decisions, the role of the researcher in the research as a researcher, the place of the researcher in the research, power relations within the research, and raising questions regarding ethical dilemmas.

- (B) Writing a reflective journal—This journal included any feelings of discomfort regarding the stay at the research field, feelings that accompanied the researcher during as well as after the interviews, personal responses, reflecting on the personal relationships with the people in the research field.

Data Collection

Ethical approval to conduct the research was received from the ethics committee of the hospital and the participants signed an informed consent. The parents were assured that the interviews were completely confidential and that they would remain anonymous.

The interviews were conducted face-to-face at a location of the interviewee's choosing. The interview was based on an interview guide (Supplemental Table 3). It included questions regarding their demographic background and then guided questions, most of which were open-ended and comprehensive, and some of which were focused questions (14). Responses were collected and audio-recorded and transcribed verbatim (interviews).

Data Analysis

Thematic analyses of the interviews were performed by each of the 2 researchers using familiarization, highlighting, and memo-writing/note taking techniques (15).

Following this, analysis and coding were performed using a 3-stage procedure: (a) interpretation of individual interviews, (b) developed themes, and (c) cross-checked and compared across other interviews (see an example of the analysis process in Supplemental Table 4). This procedure allowed comparing the codes that had been generated in each individual interview, and (d) assess the inter-rater reliability of the analysis. Ten percent of the data was randomly selected and examined by an independent rater to identify themes. These themes were then compared with those initially identified. Cohen's kappa (16) was used to calculate inter-rater agreement for the analyzed themes.

Result

Three major themes were discerned from the analysis of the interviews. These were "hope and finality," "support and reclusion," and "home and hospital."

Theme 1: Hope and Finality

This pertains to the conflict between hope and the parents' realization that their child's life will finally be coming to an end. All the parents described one specific moment in which they realized that it was the beginning of the end. They also noted that this was a moment that changed their lives and drew a line between what had been and what would be. Some examples:

- "As soon as the doctor started talking ... I knew ... I felt the ground drop out from under my feet" (I-9).
- "After the doctor said that they were stopping any conventional treatment and offered palliative care instead... I thought my child was going to die tomorrow." (I-1).

Despite their realization that this was the beginning of the end, the parents' statements also describe hope. In fact, with most of the parents, there was a constant shift between acknowledging this finality and hope for their child's life. For example:

- "Look. I understand my child's condition. ... And I'm still going to stand up against this cancer. But there are times I'm already starting to say goodbye" (I-11).

Most of the interviewees had agreed to their children receiving palliative care only, and it seems that, for the parents, the decision to keep providing palliative care was related to a way of holding on to hope. For example, one father said,

- "We are participating in some research. Maybe with this ... they're not guaranteeing us anything ... any minute now things may start working out" (I-7).

Another mother illustrates the difficulty and confusion when wavering between hope and the understanding of the finality of the end.

- "I sit here [at the hospital] for hours Some days it's okay; I still believe everything will be okay. And some days I just cry ... cry" (I-14).

Every interview included a strong and clear voice, stating how important the child was to the parent.

- "This child is my whole world ... Our whole world. What happens if he's not here?" (I-15).
- "My children are the most significant thing that I have ... I don't care about money, a house ... I just want my children to live" (I-5).

Theme 2: Support and Reclusion

This theme pertains to the dynamics and complexity of the parents' relationships with family. The interviewees described a need for practical and emotional support—from family—that often conflicted with their need for reclusion.

Family Support. All interviewees explained that they needed a lot of support in managing day-to-day activities. However, the interviewee's expressed, they also sometimes had an overwhelming need for a sense of personal independence. For example,

- "... The most stressful thing is that I'm coming home, and I can't function. I'm just so tired. I need a lot of

help to keep my house functional for the rest of the children” (I-13).

Most of the interviewees also mentioned the need for help from family on a daily basis at the hospital as well, for example,

- “I don’t want to be a burden to anyone. My family gives me their whole lives. Without their help, I couldn’t function” (I-15).

As mentioned, the help they need also includes mental support. For example,

- “My sister runs my house when I’m not around. She also gives me a lot of strength mentally ... ” (I-7).

Nonetheless, alongside their need for support, most of the parents described their need for reclusion, for example:

- “I really appreciate my family’s help, without them I couldn’t have survived this. But sometimes, when I’m here or when I go home, I need constant peace and quiet. ... I have no energy for anything” (I-13).
- “There are days when I need to escape to my bedroom. just run away ... to sleep. It does me good to get some sleep” (I-5).

Theme 3: Home and Hospital

In all the interviews, the interviewees mentioned the complex, ambiguous nature between home and hospital care. References to home care mainly concerned the level of medical security felt by the sick child and the ability of the household to meet their therapeutic function and comfort the patient and the family members caring for the child. However, there was no general consensus regarding the preferred place for child facing the EOL care or for the final death.

Many parents stated that they preferred to be in the hospital:

- “... in the hospital, God forbid if something happens, there’s always the staff to take care of it. In the hospital, you just sit You sit around, people walk by, people come to visit, I walk around with them, there is life, there are other patients Being home is difficult for me” (I-3).
- “Here, at the hospital, I can concentrate on my child. When we [i.e., the child] are at home, there is the noise of the house, there are the other children” (I-12).
- “You don’t bring this disease into the home with my young children there.” (I-15).
- “My family is the most important thing that I have I want to take care of it as much as possible, I have to

think about my other children tooThis is hard enough for them already” (I-2).

- “It’s difficult ... To lose a child ... The family is never going to be the same ... It will no longer be our ... our family, something will always be missing, incomplete ... ”(I-7).

On the other hand, some parents stated that they definitely preferred to be at home.

The parents’ own words indicate that the home is mainly a place that they wish they could go back to and that represents security they used to have. The hospital represented a place of care and medical safety and a sense of hope for a miracle or treatment that would save or at least prolong their child’s life.

Discussion

The aim of this study was to understand the experiences of parents of children with terminal cancer towards the end of the child’s life. The main themes revealed by the findings provide insight into the primary experiences of these parents in Israel. Several insights emerge from our research.

First, hope was revealed as a significant component for coping by all of the parents in this study. Clark (17) states the psychosocial aspects of cancer including the importance and impact of hope. In the literature, hope is defined as an active factor that helps people in their daily life, with managing personal crises, with finding solutions, it’s linked to a sense of control albeit in limited ways, it prevents a sense of helplessness and enables resilience (17). In this study, parents referred to 2 sources of hope: support from family and friends.

The parents in the study indicated fluctuating between resigning themselves to the impending death of their child and recurring thoughts of hope. Hope lives alongside the understanding of the impending death. This concurs with Misko and colleagues’ (18) study who claimed that “hope, perseverance and spiritual beliefs are determining factors for the family to continue fighting for the life of their child in a context of uncertainty, anguish and suffering, due to the medical condition of the child” (19). Although the parents realize that child facing the EOL is inevitable, they sometimes need to cling to the hope that something might happen that will change the verdict.

It is important to note that this form of internal discourse, which combines an understanding of their child’s condition with an attempt to cling to some hope, repeatedly emerged during every interview with the participating parents. It seems that this internal discourse constitutes the “intermediate zone” described by Salander (15) that allows them to enter and exit the existential experience of their child’s impending death. It is a coping strategy so that their child’s impending death does not completely invade their whole life. These findings are also consistent with other studies that have noted that towards EOL, cancer patients express

the importance of maintaining a normal life alongside their understanding that death is imminent (16).

Second, the findings of the study reveal the importance and centrality of the family and the child that has the illness, and the cultural role that the family and children play in the Israeli culture. This importance exists and resonates throughout the interviews with every parent. And it is reflected in every theme that was revealed in this study—the fact that the child is the center of the parent's life, and the desire expressed by the parents to do everything to keep their child alive, the importance of support from the family, and the parents' perception that the child's life would end at the hospital, which would allow them to shield the home and the rest of their family. This finding, regarding the parents' focus on the child and the family, can be explained since children and family are one of the main characteristics of Israeli society/culture.

This is evidenced by the fact that the fertility rate in Israel is high, compared to both developed and developing countries (20). The main factors driving the high fertility rate in Israel are, (a) the cultural aspect, in which the status of the family in Israel is imprinted as the cornerstones of the establishment of the Jewish state, following the annihilation of many families during the Holocaust in Europe. Interweaving the rebirth of the state of Israel and the rebirth of the family has positioned the family in Israel as truly essential, so that the value of the family is linked to continuity and rebirth (21). (b) The policy aspect, which encourages childbirth among people of all levels of education and religiosity and makes it easier for women to combine work and family life (eg, child sick days, breastfeeding time, and maternity leave). This is an essential point, since all domains of end-of-life care are shaped by culture, including the meaning ascribed to illness, the actual language used to discuss sickness and death (including whether death may be openly acknowledged), the symbolic value placed on a child's life (and death), the lived experience of pain and suffering (22). Israelis value their families and consider children central to each household unit (22), and therefore the loss of a child, according to the perception of the parents, also means the loss of a center in the family. This clarifies the importance that the parents express to shielding the home.

Another aspect of the centrality of the family is social support. Social support is a particularly important resource in coping with disease in general (23) and for cancer patients or parents of children with terminal cancer in particular (9). The findings of the current study reveal that the parents' desire or need for social support is especially important at the stage of the child's EOL (24). The parents emphasized that the support offered by family was initially a significant coping factor for them.

Third, the themes uncovered in this study reveal the essence of the parents' experiences, these experiences, according to the parents, are in constant vacillation between their 2 extremes. So, on the one hand, the parents talked about hope in their interviews, yet at the same time

they talked about the fear of the fact that their child's life may be coming to an end. The parents brought up the importance of the family and the support of the family. The parents in this study emphasized that alongside their need for support, they also felt a strong need for seclusion. In particular, the parents emphasized that as the death of the child drew near, their goals had more to do with finding some inner peace, comfort, and rest, and they had little patience for dealing with other people. This finding reflects previous findings in the literature (25).

It seems that this movement holds within it a "double awareness" (26) that seems to be essential to understanding how parents experience and cope because they are often observed simultaneously talking about 2 seemingly contradictory states (26). This double awareness is complex and, as mentioned above, has also been defined in the psycho-oncological literature as evidence of an "intermediate zone" (19).

The existence of an "intermediate zone" in which "double awareness" can be maintained may seem to be a paradox, but it seems to represent an adaptive response and a form of coping that helps these parents maintain a balance between the reality of death versus life (24) or have to choose between hope (and perhaps denial) and acceptance (and ultimate separation) (25), between support and seclusion, and between hospital and home. The findings of this study, therefore, shed light on the use of the "intermediate zone" in which "double awareness" exists for parents of children with terminal cancer toward the end of their lives (27).

There are limitations within this research. This study examined participants at one point in time when they were coping with the final stages of their children's battle with cancer disease. It would be enlightening to examine parents' attitudes and perceptions at different stages of the disease. This study also focused only on the parents' points of view; the children's, which is very important, were not taken into account.

Post-positivists challenge the idea that there is "absolute" truth of knowledge (12). Ontologically, the post-positivist paradigm maintains that reality can never be completely known.

In this study, an attempt is made to get as close to the truth as possible. It is likely difficult to exhaust, in one interview with the parents, the entire experience and the complexities of what they have been experiencing. Therefore, the findings of this study should be read carefully, with the understanding that, proving causality with certainty in explaining social phenomena is problematic and that knowledge is relative rather than absolute (12).

A number of important practical recommendations can be made for professionals treating child facing the EOL with cancer and their families, specifically palliative care staff or medical staff working in pediatric oncology departments. Understanding the "double awareness" developed by parents of children facing with EOL cancer emphasizes these parents' need for non-judgmental and attentive self-

acceptance to help them cope with their shifting states of self. In addition, in order to enable parents to make the right choices for their child facing the EOL, professionals should carefully check with the parents along the progression of their child's disease to determine the best place and most suitable way for them to say goodbye to their children.

The parent fighting the child's death and try to postponing it as much as possible, in the hospital. On the one hand, this distances the care and the impending death of the child from the rest of the family and from the other children, while on the other hand, it shifts the burden of care to doctors and the nurses in the hospital. To the best of our knowledge, in Israel, there are no sufficient training and intervention programs in medical and nursing schools, on the subject of caring for children at the EOL. This approach distances the medical staff from the patient's bed, and prevents open communication with the child's family regarding treatment options. There is significance to bring the medical staff closer to the patient's bed, which is to say, training medical staff in open communication on this subject. Because of the centrality and importance of the family in Israel, and since the fact that the death of a child constitutes a crisis for the family as a whole system, its subsystems and the family members as individuals, a crisis that puts the family in a state of emotional shock and impairs its ability to function (28). It is recommended to construct intervention programs that would accompany the whole family and not just the parents, including after the death of the child.

Due to the importance of hope as the study participants emphasized it, or in Clarke's words (17): hope is necessary at the EOL, and due to the parents' preference that their children stay in the hospital, there is some necessity to train healthcare teams working in pediatric oncology wards and providing palliative care, to teach them how to help people hold on hope, and in addition these teams need to be taught how to talk about the subject of death, or how to create communication that allows conversations about impending death. They should also be trained to evaluate hope in parents of children at the EOL and also be provided with tool aimed at the measurement/assessment of the levels of the parent's hope, for example Richard Snyder's assessment tool or Mary Nowothny's instrument.

Conclusions

This study emphasizes the cultural aspect of the Israeli society of the importance of family and of the children within the family, and of the parents' unique way of coping, of holding a dual awareness, and emphasizing that hope and support are necessary components for parents' ability to cope with their child having terminal cancer, at the EOL.

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Ethical Approval

All procedures performed in studies involving human participants were in accordance with the Ethical Standards of the hospital Review Board and approved by the ethics committee of the hospital Review Board.


Declaration of Conflicting Interests

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Supplemental Material

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